

Community Survey of Carer's: Individual epilepsy guidelines (IEG) for rescue medication

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ABSTRACT

Objective: To evaluate the effectiveness and viability of individual epilepsy guidelines as a user-friendly tool for carers of people with epilepsy and learning disabilities. In this paper the term carer refers to family carers and support workers.

Method: A retrospective survey questionnaire designed to ascertain the effectiveness and feasibility of individual epilepsy guidelines as a user-friendly tool. This was evaluated for examining clinical practice improvements and service delivery.

Results: 44 questionnaires were mailed to carers who were supporting individuals with epilepsy. There was an overall response of 42(96%).

Conclusion: This survey indicates that the IEG was a useful resource assisting carers with the management of emergency seizure events in the community.

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1. Introduction

The frequency of epilepsy in people with learning disabilities (intellectual disability) is higher than in the average general population. Epilepsy increases with the severity of the learning disability and is often refractory and complex.¹ Epilepsy is a neurological disorder characterised by a susceptibility to seizures and defined by two or more unprovoked episodes. It is a dangerous life threatening condition and a medical emergency situation with a significant morbidity and mortality rate.² There is a likelihood of seizures progressing into status epilepticus if a seizure lasts longer than 5 min.³ Studies have highlighted the benefits of the drug rectal diazepam for prophylactic intervention and remission of seizures in patients with refractory epilepsy who experience acute repetitive seizures.⁴ Diazepam medication is used to avoid status epilepticus and is an established treatment procedure. Carers can give rectal diazepam and it may avoid the necessity of sending for medical help or preventing hospital admission.⁵ Other benzodiazepines, i.e. clobazam are often prescribed prophylactically for epilepsy cluster events.⁶

Within this Learning Disability Service (LDS) the clinicians found that in the community settings many of the support

workers/carers had difficulty recognising when rectal diazepam should be administered and in what circumstances they should administer it to the patients. Few epilepsy guidelines are available for reference in clinical practice for this use. Only one epilepsy instrument by the Joint Epilepsy Council (JEC)⁷ was identified as a recommendation to the procedure. Within this tool is a standardised template for producing epilepsy guidelines for the administration of rectal diazepam (it is a generalised template to assist with epilepsy patient care). To compliment this tool the epilepsy nurse and consultant psychiatrist in the LDS devised their own epilepsy guideline instrument that has subsequently evolved. This assists carers by providing individual directions for administering emergency medication for people with learning disabilities who have refractory epilepsy, that reside in the community. This process is also supported by the NICE epilepsy document⁸ that advocates information should be provided in formats, languages and approaches, which are suited to the individual requirements for patients with epilepsy.

An important factor of the individual epilepsy guidelines (IEG) is it contributes and is intrinsic to eliminating risk or minimising adverse risks to patients who have recurrent seizures.⁹ To devise IEG's for this patient group involves a multidisciplinary approach with partnership working researchers McNeil et al.¹⁰ claim this way is a reliable form of practice in measuring assessment of risk. The learning disability service completed a service evaluation of the IEG through a survey of the carers who use this tool.

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Table 1
Epilepsy seizure monitoring-chart.

Date	Time	What happened prior to the seizure, i.e. triggers, illness, menstruation, constipation	Description What happened during seizure, i.e. jerking of limbs, cyanosed	Recovery—confused, tired, incontinent, PRN drugs given, i.e. rectal diazepam, oral clobazam. Taken to hospital	Duration of seizures	Signature
–	–	–	–	–	–	–

2. Criteria for the individual epilepsy guidelines

IEG were devised when a patient presented with refractory epilepsy or had frequent epileptic seizures approximately 1 or more a month. IEG were drawn up from the evidence of 2 weeks recorded seizure events, or 5 or more recorded episodes of a seizure. Seizure diaries were used and an epilepsy seizure monitoring-chart was created so that a narrative description log of the seizure event could be obtained when carers witnessed a seizure. The epilepsy seizure monitoring-chart is shown in Table 1.

This provided a presentation record of the type and descriptions for the individual's epilepsy seizures.^{11,12} The seizure chart was based on the behavioural approach using the antecedent behaviour consequence (ABC) analysis.¹³ This enables carers to collect as much supportive information about the individual characteristics pre and post seizure. This is important information for doctors as it aids distinguishing the preictal, ictal and postictal stages which can be difficult to detect when they co-exist with psychiatric and behavioural symptoms.^{14–16} Many studies have highlighted the complications of monitoring and diagnosing seizures due to the dual diagnosis in the learning disability population.^{17,18}

The patients IEG's were produced in consultation with carers, relatives and significant others, i.e. day/residential placements; respite care services staff and health professionals (nurses, psychiatrists, neurologists and general practitioners (GP)).

A template was created outlining the criteria for the individual epilepsy guidelines (Fig. 1).

To produce the template for the IEG a number of sources were utilised to provide an accurate description and duration for the category of epilepsy seizures.^{19–23} Some patients had their IEG's updated on 1–4 occasions for reasons such as;

- Change of epilepsy status, i.e. type or frequency.

- Carer's required further clarification/structure to carryout the procedure.
- Change of drug regime.
- Oral prophylactic antiepileptic medication was prescribed pro nato (PRN) as and when necessary, i.e. diazepam, clobazam.
- For oral diazepam prescription when individuals refuse to consent to the rectal administration route.

On completion of the individual epilepsy guidelines, a standardised GP letter was mailed out to the patient's GP/ neurologist for signed endorsement of the IEG.

3. Methodology

This is a retrospective survey questionnaire designed to ascertain the effectiveness and viability of individual epilepsy guidelines as a user-friendly tool. A 10-item 'carer's satisfaction' questionnaire was designed to obtain responses regarding the IEG (Fig. 2).

This survey was supported by the local Primary Care Trust (PCT) Clinical (Audit) Effectiveness Department. The sample was selected from an outpatient's learning disability clinic list. The participants were patients with learning disability and complex refractory epilepsy. In total 49 patients had received completed individual epilepsy guidelines during the period of 2000–2006. Of the 49 patients three people had died and two had moved out of the borough bringing the final sample to 44.

The questionnaire and an explanation cover letter giving details of the epilepsy survey were mailed to 44 carers (support workers/ family carers) for completion. A follow up telephone call was made to 2 homes in order to collect the information from carers that had not responded in writing. Data was inputted onto Microsoft Excel and analysed using SPSS for Windows, version 15.

4. Results

42 out of 44 questionnaires were returned, which gave an overall response rate of 96%. Analysis was carried out based on the 42 returned questionnaires.

In the United Kingdom a national training standard has been established by the Joint Epilepsy Council for the administration of rectal diazepam. It outlines the requirements necessary to carry out this procedure. In view of this Barnet Learning Disability Service (BLDS) had produced a borough-wide epilepsy protocol and epilepsy training programme²⁴, which complies with these standards. In answer to question 1, from the 'Carer Satisfaction' Questionnaire' 26(62%) carers had received Barnet Learning Disability Service epilepsy training, with 16(38%) not receiving the training. Fig. 3 shows how often the IEG is utilised when the patient has a seizure.

There were 34(80%) carers who said they *always* use the epilepsy guidelines when a patient has a seizure. Only 2(5%) carers reported that they *usually* use the guidelines, 2(5%) *sometimes* and 2(5%) *never*, 2(5%) carers did not respond to this item in the

Confidential

Date:
Name:

Type of seizure

Possible Triggers

Description of seizures: **Duration:**
Tonic Clonic, Tonic, Atonic, Absence, Myoclonic, Simple, Complex, Partial

ACTION

Rectal Diazepam to be administered when
has i.e. **Tonic Clonic** 1 seizure lasts longer than 4 minutes, 2 seizures in succession or 2 seizures within 6 hrs.
PROPHYLACTIC (PREVENTION) PRN. Oral MEDICATION

Residential / Day Services / Schools (Communication)

Current Medication
PRN Medication

INDIVIDUAL EPILEPSY GUIDELINES (IEG) QUESTIONNAIRE

1. Have you received epilepsy training from Barnet Learning Disabilities Service?
2. Do you use the individual epilepsy guidelines when the client/patient has/had an epileptic seizure?
3. Did you find the individual epilepsy guidelines helpful?
4. If yes/no in what way?
5. Did you find the individual epilepsy guidelines easy to understand?
If no, how can this be improved?
6. Did you understand the language (terminology) use?
If no, what words could you not understand?
7. Have you become more familiar with the client's/patient's epilepsy, as a result of the individual epilepsy guidelines?
8. Since the guidelines have been issued have you administer Rectal Diazepam to this client/patient?
 - 8a. Are you certain when to administer PRN Rectal Diazepam?
 - 8b. Are you certain when to administer PRN Oral Clobazam?
9. Have the epilepsy guidelines made it easier for you to know when/how to administer Rectal Diazepam?
10. Is there any other information that you would like to be included in these individual epilepsy guidelines?
If yes please list:

Fig. 2. 10-item 'Carer Satisfaction' Questionnaire Individual Epilepsy Guidelines. Responses were in the format of YES/NO with the exceptions of Questions 4, 5, 6 and 10 which, dependent on the answer given, asked for the respondents reasoning.

It is important to obtain the carers opinions and experiences of the IEG. In answer to question 3, 41(98%) respondents agreed that they found the IEG's helpful. The reasons for this were explored further in question 4. Fig. 4 shows a summarised breakdown of the reasons given.

The most frequent comment made by 12(38%) carers was that the IEG's aided in the management of the client's epilepsy and 10(31%) deemed that they aid the administration of medication. 6(19%) carers felt that the IEG are good for staff to extend their understanding. 2(6%) mentioned that the IEG help the needs of the individual to be met and 1(3%) that it gives confidence to the carer. 1(3%) declared that the guidelines need upgrading. Carers were then asked *whether or not they found the IEG easy to understand, if they understood the language used, and had they become familiar with the type of epilepsy due to the IEG's.*

Percentage of carers who use epilepsy guidelines

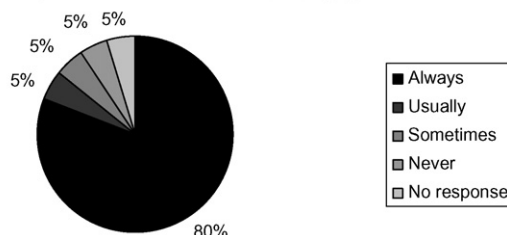


Fig. 3. 'Carer Satisfaction' Questionnaire Responses to Question 2. This

Fig. 5 shows that 39(93%) carers found the IEG's easy to understand, 41(98%) carers understood the language used and 37(88%) carers have become familiar with the type of epilepsy due to the IEG's.

Fig. 6 shows that 19(45%) carers administered rectal diazepam to the patients after the IEG's were issued. The 22(52%) may represent that patient/client seizures were controlled and therefore did not require rectal diazepam. 40(95%) carers felt certain when to administer rectal diazepam and 36(86%) carers felt that

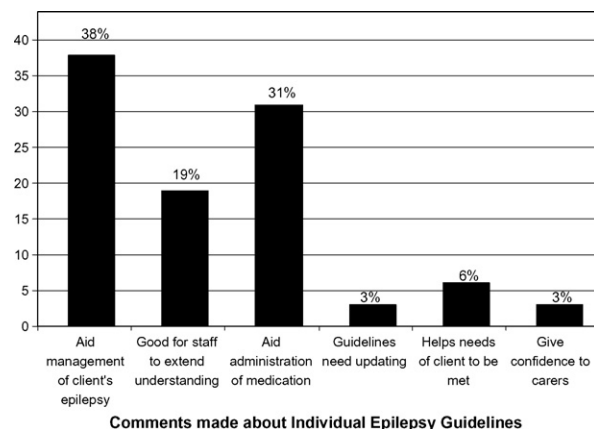


Fig. 4. 'Carer Satisfaction' Questionnaire Responses to Question 4. This

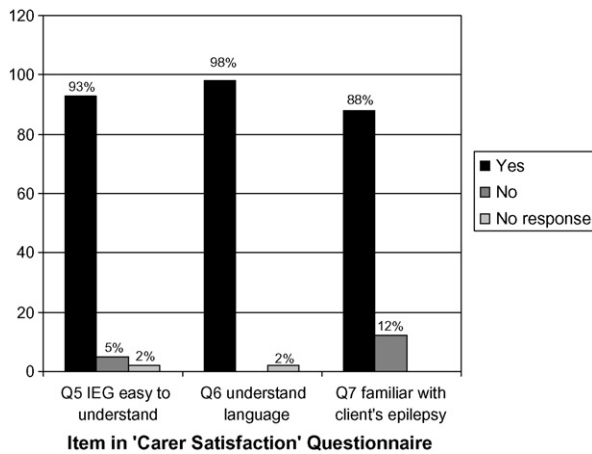


Fig. 5. 'Carer Satisfaction' Questionnaire Responses to Question 5, 6, and 7. These demonstrate whether or not carers found the IEG easy to understand, whether or not they understood the language used and whether or not they have become familiar with the type of epilepsy due to the IEG's.

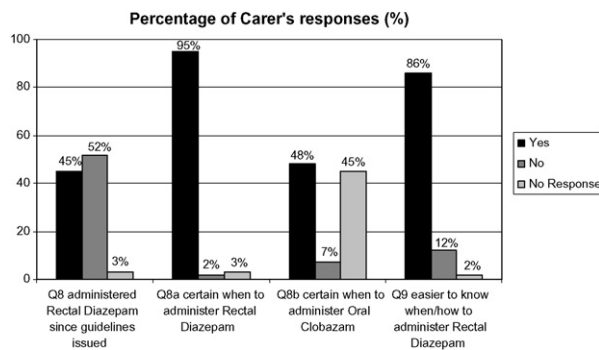


Fig. 6. 'Carer Satisfaction' Questionnaire Responses to Question 8, 8a, 8b, and 9. These demonstrate whether or not carers were certain when to administer PRN rectal diazepam and PRN oral clobazam and whether or not the IEG has made it easier to know when to administer rectal diazepam.

the IEG had made it easier to know/how to administer rectal diazepam. Twenty patients (48%) were prescribed oral clobazam medication and were certain when to administer oral clobazam medication. The other 19(45%) were not prescribed this medication.

The last question 10 from the carer's satisfaction questionnaire asked *if there was any other information they would like included in the IEG*. 6(14%) carers wanted the IEG updated.

5. Discussion

The survey results demonstrate that 34(80%) of the carers utilised the IEG's every time an individual had an epileptic seizure. This suggests as a clinical working tool it was effective for assisting many carers with the application of PRN medication. 39(93%) carers found the IEG's easy to understand and 37(88%) carers were more informed about carrying out the procedure of administering rectal diazepam, as a result of the guidelines. There were comments that indicated it was helpful to have the IEG as a reference for regular and new support workers that supervise people living in the community. It enabled carers to be familiarised with the patient's seizure pattern and epilepsy management. These factors are confirmed by 41(98%) carers claiming to understand the

The study mentioned above by Wulf of evaluating seizures highlighted that observational data will differ when carers are trained by different methods. Results from this survey indicate that 26(62%) carers had received the local LDS epilepsy training. This provided assurance that many carers had attained adequate knowledge to record the patient's seizure events which supports the clinicians formulating the IEG's.

In this survey 40(95%) carers are certain when to administer rectal diazepam and 36(86%) claim that the IEG's have made it easier for clarification. This is very positive as Shafter²⁵ noted it is crucial caregivers can discriminate between ordinary or cluster seizures to identify the necessity for PRN rectal diazepam. This demonstrates the IEG's are a functional tool that carers can refer to when a patient has recurrent seizures.

Of the total sample of 42, only 23 individuals were prescribed oral clobazam medication, alongside the prescription of rectal diazepam. The responses indicated that 20(93%) carers were certain when to administer oral clobazam. Only 3(7%) of the responses indicated they were uncertain. This is very important as often this antiepileptic drug is prescribed for patient's prophylactically to reduce potential seizures.

In the questionnaire the most frequently suggested change to the IEG was the need for regular updating. This is very plausible as often when patients attend the doctor's outpatient clinic their health circumstances may have changed from the previous consultation. A patient's epilepsy condition may be unstable or changes occur requiring a medication review, etc. As a result there are occasions the IEG will need to be altered to reflect the patient's clinical status.

From the survey it is suggested that the IEG's may act as an educational resource. This is supported in the survey by 37(88%) carers agreeing that they have become familiar with their clients epilepsy due to the IEG's. This is a very positive point as education is fundamental in raising patient care.²⁶

The IEG's are an influential communication resource for sharing information with health professionals. When the patient has a seizure in the community it could be utilised as additional data on admission to hospital as a proactive crisis plan, i.e. Accident Emergency Department, for medics/personnel.²⁷ This is also supported by the response that 34(81%) carers referred to the IEG when a person in their care had a seizure.

A limitation of the IEG's is that they are very comprehensive and initially time consuming. Principally it is due to the frequent liaising and conferring with the patient/carers and significant others to produce them. This process is essential to ensure that the carers understand and are satisfied with the IEG's. Fortunately the advantages compensate for this as it increases patient/carers satisfaction as affirmed by the results of this survey, prevents hospital admissions, and enables the person to receive emergency treatment by familiar people.

6. Conclusion

This survey indicates the IEG's are a viable resource. The survey illustrates that carers and patients benefit from the 'hands on' person centred approach towards epilepsy care. This study shows that multidisciplinary collaborative working method is important for achieving carer and patient agreement.

These IEG's could be viewed as a means of minimising patient/carers anxieties and stress during emergency events and reduce the need for hospital admissions. It is possibly a cost saving scheme with likely economic savings made to the National Health Service (Primary Care Trust) by decreasing the number of patient admissions to hospital.²⁸ The International League Against

considerations of epilepsy systematically²⁹ and this survey provided one avenue for this.

The intention is to provide a structured approach for devising epilepsy guidelines for the learning disability service. The plan is in the future for adult learning disability patients to use buccal midazolam medication (an alternative to rectal diazepam which is less intrusive) and develop guidelines using this process.³⁰

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