



# Epilepsy clinic services, nice guidelines and patient satisfaction—An audit

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## KEYWORDS

Epilepsy;  
Audit;  
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## Summary

**Objective:** To audit the performance of the paediatric epilepsy services in a district general hospital based on NICE guidelines and parent satisfaction.

**Design:** Retrospective audit.

**Setting:** Paediatric epilepsy clinic in a district general hospital.

**Patients:** Consecutive children ( $n = 54$ ) with epilepsy attending the paediatric epilepsy clinic over a 4-month period.

**Methodology:** Data from hospital notes was recorded in standardized study forms, which was subsequently entered into database and analysed independently. A parent/patient satisfaction survey was also conducted over the same period involving the same study population by sending out a postal questionnaire.

**Outcome measure:** NICE epilepsy audit criteria and patient/carer satisfaction measured using the standards published by Webb et al.

**Results:** The results show that the service achieved almost all the key targets set out in the NICE guidelines but performed less well in the parent satisfaction survey.

**Conclusion:** This audit suggests that in addition to NICE guidelines, an evaluation of parent/patient satisfaction should form part of assessment of the quality of paediatric epilepsy service.

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## Introduction

Epilepsy is the most common paediatric neurological disorder with an overall incidence of about 4 per 1000 children.<sup>1</sup> Across the United Kingdom, care for children with epilepsy is provided mainly in general paediatric clinics.<sup>2</sup> In 2004, National Institute for

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Clinical Excellence (NICE) and the National Collaborating Centre for Primary Care (NCCPC) issued a clinical practice guideline on the diagnosis and management of epilepsy in children and adults, which set out comprehensive standards for the care of those with epilepsy. NICE guideline does not include measuring Patient/Patient satisfaction with the service being delivered.

In Swindon (Wiltshire), a paediatric outpatient epilepsy service was set up in 1998. The performance of the service was audited annually using the criteria published by Webb et al. in 1998 until 2004 and in 2005 the newly issued NICE guidelines were used.<sup>3,4</sup> In addition to the audit of the NICE guidelines, a parent/patient satisfaction survey was also done.

The objective of this audit is to evaluate the performance of the paediatric epilepsy services in a district general hospital using NICE guidelines and parent satisfaction.

## Patients and methods

The Great Western Hospital, Swindon is a district general hospital that serves a population of about 300,000, which includes approximately 68,000 children below 18 years of age. There are eight consultant paediatricians. One of the consultant paediatricians with special interest in neurology runs the epilepsy services along with a team of two part time specialist paediatric epilepsy outreach nurses and a consultant child psychiatrist.

The paediatric outpatient epilepsy service, conducted once weekly serves 178 children with epilepsy. In addition there are 12 clinic sessions a year done jointly with a visiting consultant paediatric neurologist and four joint clinics with a Physician Neurologist for young adults with epilepsy. The hospital has its own CT, MRI and EEG services. A tertiary consultant neurophysiologist interprets all the EEG records. The radiologist interprets all of the neuro-radiology images and most are also interpreted by the neuro-radiologist in the regional centre.

This audit was conducted retrospectively over a 4-month period from March to June 2005 at the Great Western Hospital, Swindon, Wiltshire. All the children who attended the service during the study period were included. Children in whom diagnosis of epilepsy had not yet been established were excluded. The standards set by the NICE<sup>4</sup> were used as the standards for this audit and the information was obtained from the medical and nursing records. To avoid bias, data was recorded in standardized study forms by one of the authors not directly

involved with epilepsy care. The data were subsequently entered into database and analysed by a member of the clinical audit department.

In addition, an anonymous child and parent/guardian satisfaction survey was also conducted over the same period involving the same study population. The children and parents/guardians were asked to return a postal questionnaire relating to staff courtesy, information provided, and clinic visits. The degree of satisfaction was scored on a Likert scale of 1–5.<sup>5</sup> Scores of four or more were considered to imply satisfaction. Standards that were not met 90% of the times (maximum threshold of standard set for quality indicators for epilepsy in the new GMS Contract) were considered as having been failed. The questionnaire was sent by the Clinical Audit department independently of the clinicians and they also collated the results.

## Results

During the period, 60 children attended the paediatric epilepsy clinic. Fifty-four of these children were diagnosed as having epilepsy. Six other children were undergoing further investigations. Twenty-three were girls. The demography of the study population is given in Table 1. The audit criteria under each key priority are given in Table 2.

### Key priority 1: children with recent onset seizures should be seen urgently by a specialist within 2 weeks of referral

In our clinic, only 24 of the 60 (40%) children with recent onset suspected seizures were seen by the

**Table 1** Demography of the study population

Total number of children	54
Sex	
Boys	31
Girls	23
Age	
<5 years	10
6–10 years	16
11–16 years	28
Seizure type	
Primary generalized epilepsy	26
Complex partial epilepsy	12
Absence epilepsy	11
Simple partial epilepsy	2
Myoclonic epilepsy	2
Benign rolandic epilepsy	1

**Table 2** Audit results

Standards		Number (%)
Key priority 1: all individuals with recent onset suspected seizure should be seen urgently by specialist		
Criteria	Individuals with suspected recent onset seizures should be seen within 2 weeks of referral	24/60 (40%)
	Named specialist who established the diagnosis of epilepsy.	54/54 (100%)
	Whether or not AED therapy was prescribed.	54/54 (100%)
	Details of the prescription	54/54 (100%)
	AED therapy was prescribed in consultation with the individual and family and/or carers.	54/54 (100%)
Key priority 2: seizure type(s) and epilepsy syndrome, aetiology, and co-morbidity should be determined		
Criterion	Seizure classification using a multi-axial classification scheme	54/54 (100%)
Key priority 3: AED treatment strategy should be individualised		
Criteria	Appropriate first line drug should be used depending on the type of seizure	53/54 (98.0%)
	Before considering the first line drug to have failed: maximal dosage of the first line drugs has been used	23/25 (92.0%)
Key priority 4: all individuals with epilepsy should have a comprehensive care plan		
Criterion	All individuals with epilepsy should have a agreed care plan	54/54 (100%)
Key priority 5: all individuals with epilepsy should have a regular structured review		
Criteria	Review in the previous 12 months.	54/54 (100%)
	Seizure frequency	54/54 (100%)
Key priority 6: all individuals with epilepsy should have access to information		
Criterion	Individuals should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations.	43/54 (80%)
Key priority 7: advice on pregnancy and contraception		
Criterion	Advice on pregnancy and contraception to all adolescent girls	12/12 (100%)
Key priority 8: all individuals with uncontrolled seizure should be referred to tertiary services soon		
Criteria	All individuals who have indications for referral to tertiary services were referred.	27/27 (100%)
	Individuals were referred to tertiary services were seen within 4 weeks	0/27 (0%)

specialist within 2 weeks. All the other audit criteria for this key priority were met in 100% of children (i.e. named specialist who established the diagnosis of epilepsy, Whether or not AED therapy was prescribed, details of the prescription, and whether AED therapy was prescribed in consultation with the individual and family and/or carers).

### Key priority 2: seizures and/or epilepsy syndrome classified using a multi-axial classification scheme<sup>6</sup>

The standard for this key priority area is that the records should document the proper use of multi-axial classification in order to determine the seizure type(s) and epilepsy syndrome, aetiology, and co-morbidity. All the 54 (100%) children had their

condition classified properly within the limits of available EEG and clinical data.

### Key priority 3: AED treatment strategy should be individualised

The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication, co-morbidity, the individual's lifestyle, and the preferences of the individual, their family and/or carers as appropriate. Criteria to evaluate this area are (1) the type of first line drug used and (2) maximal dose used before considering the first line drug has failed. 98% (53 out of 54 children) were started on appropriate first line medication. A total of 25 children needed their AED to be changed, and in 23 of these, the maximal

dosage of the first line drug has been tried before changing to or adding on another drug. In two other children, the records did not document a reason for change of antiepileptic drug.

#### **Key priority 4: individuals with epilepsy should have a comprehensive care plan**

All of the study children (54) who were diagnosed with epilepsy had a comprehensive care plan, which had been agreed with the parents/carers as appropriate.

#### **Key priority 5: all individuals with epilepsy should have a regular structured review**

The criteria set by NICE to evaluate this aspect of the paediatric epilepsy care include (1) every one should have a review in the previous 12 months (2) there is proper documentation of seizure frequency. All the 54 children (100%) with epilepsy had a structured review by the paediatric epilepsy team within the previous 12 months. Though all the children had their seizure frequency documented, the seizure free interval has not been documented clearly.

#### **Key priority 6: all individuals with epilepsy should have access to information**

All the patients and their parents/carers who attend the paediatric epilepsy service have wide access to information about counselling services, voluntary organisations, epilepsy specialist nurses and appropriate investigations (in the form of leaflets) in the

unit. However, the records have shown clear documentation of access and provision of information in only 80% of the children.

#### **Key priority 7: advice on pregnancy and contraception**

Out of the 54 children who were included in this audit, 12 were adolescent girls. The paediatric epilepsy nurses provide advice on pregnancy and contraception in the clinic. There was documentation about the advice having been given in the medical notes of only one girl. Such advice is normally recorded in the community nursing notes and there was 100% documentation in the nursing notes.

#### **Key priority 8: all individuals with uncontrolled seizures should be referred to tertiary services**

Twenty-seven children had uncontrolled seizures and all of them were referred appropriately to tertiary services. But none of them were seen within 4 weeks, though telephone advice was sought in the case of four children within the 4 weeks.

#### **Performance areas not suggested by NICE but studied in the current audit**

These included yearly reference to development/school progress, and weight and height. In 52 of the 54 children, reference had been made to the development/school progress of the children. Weight and height was recorded in the notes of 52 and 49 of the children respectively.

**Table 3** Parent satisfaction (affirmative response)

	Yes (N = 22)
<b>Courtesy</b>	
Reception staff friendly and polite?	81.80%
Nursing staff friendly and polite?	89.10%
Medical staff friendly and polite?	90.00%
<b>Communication</b>	
Epilepsy explained?	78.20%
Enough information to understand Epilepsy?	78.20%
Doctors easy to talk to?	81.80%
Questions listened to?	82.70%
Questions adequately answered?	74.50%
<b>Clinic visits</b>	
Waiting time acceptable?	69.10%
Are clinic visits; too frequent, too seldom, just right?	92.40%, Just right
Time spent with the Doctor; too long, too short, just right?	92.40%, Just right
Do you feel clinic visits are worthwhile?	84.50%
Are you happy with your child's care?	80.90%

## Parent/carer satisfaction

The questionnaires concentrated on three different areas—(a) staff courtesy, (b) communication and (c) clinic visit. Parents were requested to answer 13 questions addressing these areas. A total of 54 questionnaires were sent to the parents. Only 22 of these were returned.

Just fewer than 80% of the parents felt that the staffs were courteous and considerate. However, >20% of the parents felt that: (1) the condition was not adequately explained, (2) enough information was not given or (3) adequate time was not available to answer all their questions. Most patients were happy with the frequency and timing of the clinics but >30% of the parents found the waiting time in the clinic unacceptable. The performance in all of these areas is shown in Table 3.

## Discussion

The main objective of this audit was to study the quality of paediatric epilepsy care in our district general hospital measured against the national standards and also from a service user's perspective. To our knowledge, this is the first audit evaluating paediatric epilepsy clinic service using the NICE guidelines and parent satisfaction survey.

NICE guidelines provides the audit standards to enable clinicians to restructure and adequately resource epilepsy services based in district general hospitals.<sup>7</sup> There is a paucity of published data with regards to standards set by NICE for measurement of quality of care for children with epilepsy. Most of the recommendations by the NICE guidelines except for the recommendation about evaluation by specialist within 2 weeks, individualisation of antiepileptic therapy and monotherapy are based on evidence other than category A. In our audit, only 40% of the children could be seen by the specialist urgently. Given the variable spectrum of epileptic disorders, it could be argued that not all children with suspected recent onset seizures need to be seen within 2 weeks unless the referral history indicates otherwise. If this key target were to be achieved, the general paediatrician may not be able to fulfil his other duties. A significant proportion of the new referrals are following emergency admission to the children's ward or attendance in casualty department where the child has already seen by a Consultant Paediatrician. This standard may need to be reviewed in the context of a district general hospital.

NICE has been criticised for its over-reliance on evidence-based medicine. However, lots of the recommendations for treatment of epilepsy is not

based on type 1 evidence and some are opinion based. NICE's recommendation that children with uncontrolled seizures should be referred within 4 weeks is one which lacks such evidence. Many children who have uncontrolled epilepsy even after a trial of two first line medications may vary widely in their seizure frequency and related adverse effects and not all of them may need to be seen within 4 weeks in the tertiary neurology centre. Debate and clarification of such issues, i.e., such as how NICE reach its conclusions, impact of its guidance on the National Health Service and compliance with NICE guidelines have been well discussed by Dent and Sadler.<sup>8</sup>

Guidelines from expert bodies such as NICE help in the provision of good quality care to the patients. Regular audit of such clinical care being delivered against NICE guidelines would help reducing unnecessary investigations and therapeutic practices. However, unless such audit includes measuring parental/patient satisfaction, clinicians may not achieve the necessary degree of compliance with the therapy. Webb et al. have indicated in their article that patient satisfaction is in itself an important prerequisite for a high quality of care as individuals who are more satisfied are more likely to comply with treatment and clinic appointments. A recent study on parents' and physicians' perceptions of childhood epilepsy identified that there is a low degree of concordance between parents' and physicians' perceptions for global, medical and everyday aspects of epilepsy.<sup>9</sup> In their studies, Becker et al. and Korsch et al. have shown that parental dissatisfaction had been associated with poor use of medical services and poor compliance with medical advice.<sup>10,11</sup>

One of the weaknesses of this audit is the poor response from the parents with only 40% choosing to express their opinions despite the clinical audit department sending reminders. This low return rate might be because parents were just getting on with their life or it may indicate that the patients were too displeased to return the questionnaire. It is also possible that patients were happy with the services and did not bother to send back the questionnaire. An audit based on case notes alone cannot assess non-recorded activity and so the findings may not be entirely comprehensive.

The current audit highlights the need for understanding the patient perspective and education of healthcare professionals responsible for epilepsy services about this need. Though, with the advent of the NICE guidelines, basic standards for the medical management of children with epilepsy have been drawn, which can easily be audited from medical records, its main usefulness is to identify achievable improvements in quality of care from a physician's perspective. However, if we do not address the key

issue of parental satisfaction, it is likely that the compliance of therapy is likely to suffer in the long run.

Our preliminary data suggests the need for a larger and detailed study looking at epilepsy care from a patient's perspective. Such a study should be used to draw nationally agreed standards for measuring the quality of care given to children with epilepsy from a patient/parent's perspective which should be made integral part of any evaluation of paediatric epilepsy care.

NICE guidelines help clinicians to improve the standards of care. This audit proposes that in addition to NICE guidelines, an evaluation of parent/patient satisfaction should form an integral part of assessment of a Paediatric Epilepsy Service. A future survey incorporating the above key points and questions regarding quality of life might yield valuable additional information.

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