



Implementing epilepsy guidelines within a learning disability service

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Implementation;
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Summary

Purpose: To investigate the usefulness of the implementation of NICE guidelines when reviewing care within an outpatient learning disability service.

Methods: We set up a multi disciplinary specialist epilepsy clinic and reviewed all patients with a diagnosis of epilepsy using a specific assessment document based on NICE guidance. We then audited clinical documentation prior to and after the implementation of the clinic.

Results: We reviewed 23 patients and found that implementing NICE guidelines showed improvements to individuals' seizure assessments and epilepsy management. When comparing specific areas related to NICE implementation we found that 83% compared to 6% of patients had accurate name and detailed seizure descriptions. We made changes to seizure diagnosis in 76% of patients and improved the level of recording of seizure frequency and severity. Finally 91% compared to 50% of consultations led to changes in treatment plans.

Conclusion: We found that implementing the NICE guidelines allowed us to use a systematic approach to epilepsy management, which in turn led to identifiable improvement in documentation and patient care.

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Introduction

Learning disability

The World Health Organisation¹ defines learning disability (mental retardation) as, a condition of arrested or incomplete development of the mind

characterised by the impairment of skills and overall intelligence in areas such as cognition, language, motor and social abilities. The individual severity of learning disability may vary as detailed below (Table 1).

Epilepsy and learning disability

The relationship between epilepsy and learning disability is complex. Some specific epilepsy syndromes

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Table 1

Severity of learning disability	IQ range	Mental age
Mild	50–69	9 to under 12 years
Moderate	35–49	6 to under 9 years
Severe	20–34	3 to under 6 years
Profound	Below 20	Below 3 years

Adapted from ICD 10, Chapter 5.

are associated with learning disabilities, for example Lennox–Gastaut syndrome. Epilepsy is 20 times more common in people with a learning disability than the general population. The prevalence of epilepsy has a direct link to the severity of learning disability. The risk of epilepsy rises from 7% with mild learning disability to as high as 67% if the person has severe learning disability.

Diagnosis of seizure type can be extremely difficult in individuals with a learning disability. Seizures do not always conform to classic definitions and seizure activity needs to be differentiated from stereotypical behaviours.^{2,3} This is exacerbated by the possibility of communication difficulties. Investigations may be more difficult to complete.

People with a learning disability are more likely to have⁴:

- More than one seizure type.
- Treatment resistant epilepsy.
- Prescribed polytherapy.
- Susceptibility to unidentified side effects of AED's.

Clinical guidelines

The NICE guidelines aim to give advice about the diagnosis, investigation and management of epilepsy.⁵ They make specific reference to people with a learning disability highlighting the importance of risk assessment and specialist multi disciplinary working.

They were predated by various learning disability specific documents. The Valuing People document and IASSID clinical guidelines both make reference to epilepsy management.

Frost et al.⁶ stated that, guidelines are of little use if they are not recognised, implemented and supported. The study was therefore designed to investigate the above statement with reference to the NICE guidelines.

Services that were in place prior to setting up the clinic

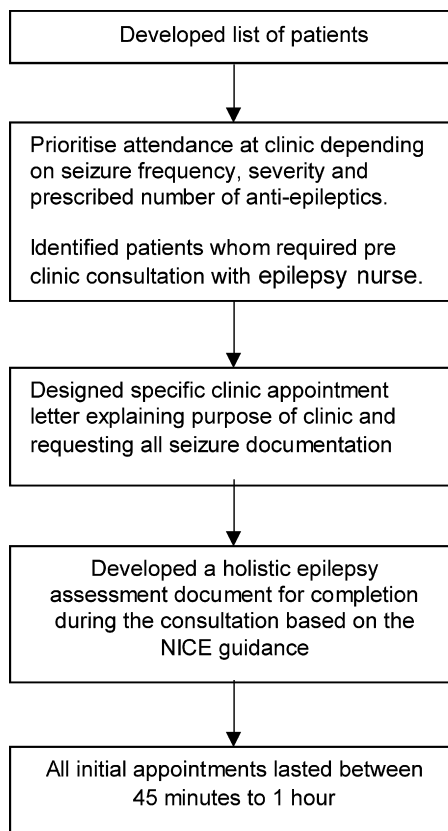
Prior to the start of this study patients were seen at the learning disability mental health outpatient clinic. This clinic focused primarily on mental health disorders.

There was no identified database of people whom attended for management of their epilepsy. Therefore the first task was identifying these people within the general outpatient population.

Objectives of the clinic and the audit

- To carry out a multi disciplinary review of epilepsy care in line with NICE guidelines.
- To achieve a detailed record of past and present epilepsy care and update treatment and management plans.
- A comparison of clinical documentation before and after the introduction of the NICE guidelines.
- An assessment of the practicality of implementing the NICE guidelines.
- Suggesting relevant recommendations arising from the audit.
- To raise awareness of the NICE guidelines.

Process of initiating the NICE clinic



Methodology

The guidelines were implemented through the introduction of a specialist multi disciplinary epilepsy clinic.

We reviewed all patients whom had a diagnosis of epilepsy within 1 consultant’s catchment area of the learning disability service.

Pre clinic consultations with the epilepsy specialist nurse were arranged at home if patients met the following criteria:

- No record of early epilepsy history.
- Seizure documentation not brought to previous clinics.

This involved gathering essential information about epilepsy history, whilst highlighting the importance of attending the clinic with relevant documentation. This aimed to improve the usefulness of time spent at the NICE clinic.

Patients, carers and relevant other professionals, usually community nurses or social workers were invited to attend a 45 min consultation. We saw a total of 23 patients, between February and September 2005. This was a time-limited one off consultation.

The development of an assessment document enabled the clinic to assess both the medical, nursing and social needs of the patients and carers. Social needs assessed included, social situation, daily living skills, promoting independent living and an assessment of the persons understanding of their epilepsy, as in line with NICE guidelines.

Amongst other criteria, we focused on:

- Seizure descriptions.
- Seizure type.
- Seizure frequency and severity.
- Relevance of seizure description and type identified.
- Aetiology and co-morbidity.
- Investigations.
- Review of past and current treatment.
- Risk assessment.

We also developed an audit tool to evaluate the clinic. The above list was reflected in this. We collected data from two points in time.

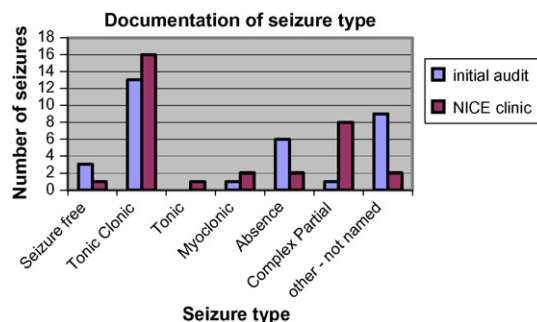


Chart 1

First—Most recent clinic visit prior to October 2004 (publication of NICE guidelines). The information was obtained from the GP letter and the written notes. This is referred to later as the initial audit.

Second—Audit of the epilepsy clinic. The information was obtained from the assessment document, GP letter and the written notes completed by either the doctor or nurse. This is referred to later as the NICE clinic.

The data was analysed focusing on the documentation held within clinical notes, we did not directly compare data for individual patients. For example, we looked at documentation of seizure frequency as a whole for each point in time and then compared the two figures.

Results

Seizure assessment

We identified fewer patients (39%) with multiple seizure types, compared to the initial audit (50%). Single seizure type increased from 50 to 61%. More tonic-clonic and complex partial seizures were identified (Chart 1).

Thirty-one seizures were identified in the initial audit; only 6% included a detailed seizure description and seizure type. Following the NICE clinic 80% of seizures included a name and matching detailed description (Chart 2).

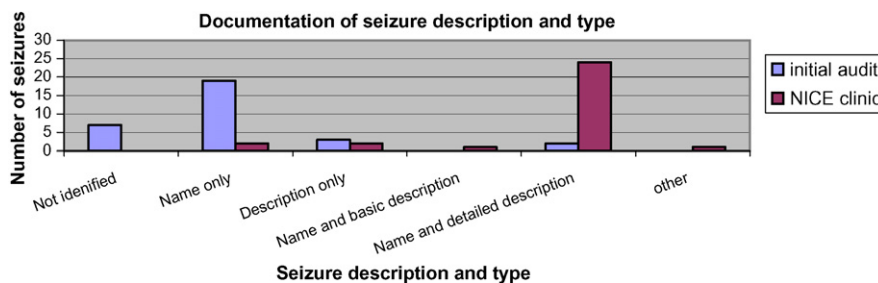


Chart 2

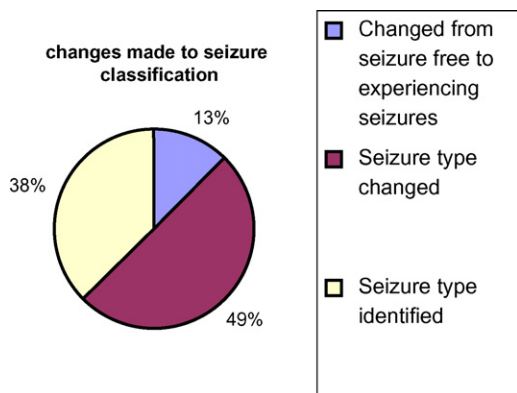


Chart 3

During the consultation we reviewed the information recorded regarding seizure classification. Carers were asked to identify the term they used when completing seizure documentation (e.g. Grand Mal) and then to describe/demonstrate the physical symptoms observed. The most common change occurred when carers recorded an absence seizure but described/demonstrated a complex partial seizure.

We made changes to 76% of either seizure descriptions or seizure types. This led to an improvement in choosing the most appropriate anti-epileptic prescribed as will be detailed.

Later, Chart 3 emphasises the point, while also highlighting that over a one-third of patients required seizures types to be further detailed, as the documentation contained words such as fit or seizure. A video recording of the event was requested in cases where classification was uncertain.

The initial audit showed that clinicians were good at recording seizure frequency (78%) although only 57% documented the severity. This was something that the NICE clinic focused on therefore all patients seen in the NICE clinic had recording regarding seizure frequency and severity.

Aetiology, co-morbidity and investigation

We aimed to identify the aetiology of the epilepsy other than having a learning disability. Whilst accepting that having a learning disability could be seen as an aetiology we were looking to identify other causes. One patient had an identified epilepsy syndrome, which required lifelong medication. This person was seizure free when seen at the clinic. We also looked at co-morbidities, 48% of the patients seen in the NICE clinic were identified to have other co-morbidities, compared to 13% initially. This was further broken down, and we identified the existence of a significant co-morbid mental health diagnosis, 91% of patients seen compared to 59%.

As an approach to holistic epilepsy management we tried to identify whether people's epilepsy was appropriately investigated.

One of the clinics objectives was to produce an accessible document whereby all information related to history, investigation, diagnosis, and management up to that point would be stored. This led to a complete review including asking about past investigations and treatments.

We considered ECG, EEG, MRI or CT and relevant blood tests. We looked at when EEG was performed and the results. The initial audit highlight only 2 EEGs, of which both were standard EEG's carried out in the last year, and both results was abnormal. For the NICE clinic, 22 EEG's were identified, 7 were completed within the past year and all were done within the last 10 years. Fifty-nine percent of these showed an abnormal result. We found that all blood tests performed were appropriate to patient care.

Treatment

The initial audit showed that the majority of patients were prescribed either 1 or 2 anti-epileptic drugs (AED's) (Chart 4) although it has to be acknowledged that 14% of all patients did not have medication documented and 36% had medication prescribed that was not relevant to the seizure type recorded. On audit of the NICE clinic all letters included an accurate and up to date list of medication. Only 4% had medication prescribed that was not relevant to seizure type, however a plan for the reduction of this medication was initiated.

Comparing prescribing patterns between the two dates is difficult due to treatment changes that were made during the NICE clinic and poor documentation in the initial audit (Chart 5). Following the NICE clinic 20 more prescribed medications were identified; this was due to improved accuracy of recording of medication, also 91% of patients seen had changes made to treatment plans. Of that 65% had changes made to current medication, 35% had new medication introduced.

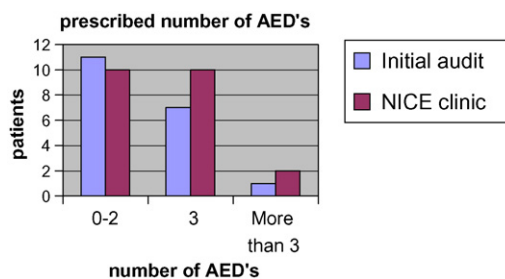


Chart 4

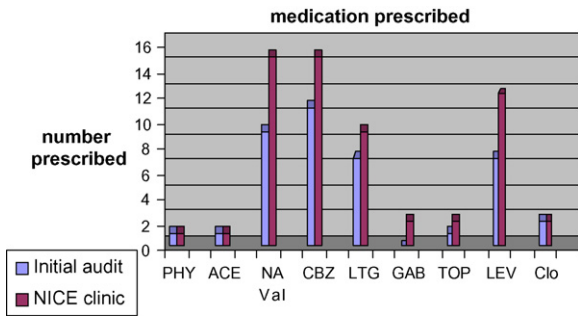


Chart 5

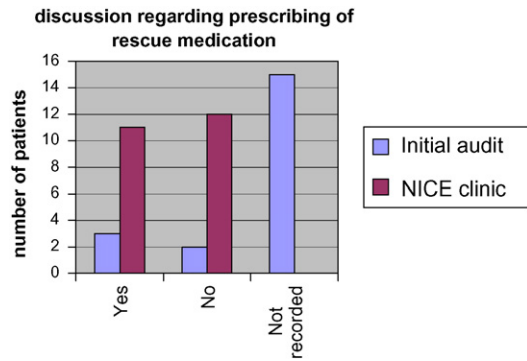


Chart 8

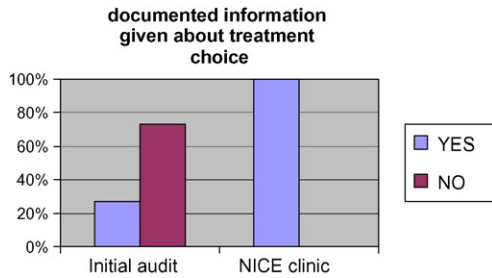


Chart 6

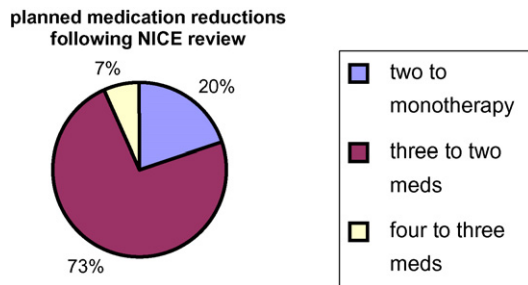


Chart 7

Improvements were noted in the documented evidence regarding treatment choice (Chart 6).

Chart 7 summarises the reductions planned to medication resulting from review at the NICE clinic.

Another issue within learning disabilities are the prescribing patterns of rescue medication. The initial audit showed that with 75% of patients

there was no documentation as to whether rescue medication was used (Chart 8).

Risk assessment

One of the main recommendations from the NICE guidelines, specific to learning disabilities, was the need for risk assessments in identified areas. We found that 100% of patients had risks discussed and of these 68% had risks identified. This was compared to 4.5% in the initial audit. For those where risks were identified appropriate referrals were made.

Outcomes

As a result of attending the clinic most patients had a change in their care management, of that; a change in seizure classification was most frequent. The major outcomes of the NICE clinic are summarised in Chart 9.

Discussion

Although there is debate regarding the effectiveness of specialist epilepsy services,⁷ we found the setting up and running of the specialist epilepsy clinic a rewarding experience. It allowed for a more detailed focus on the persons' epilepsy and related

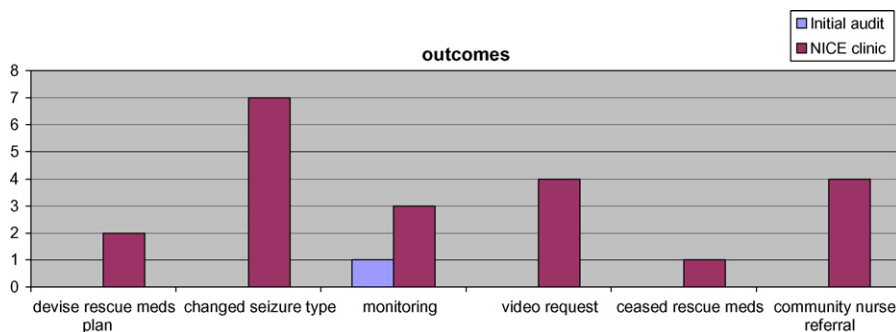


Chart 9

issues, especially due to the multidisciplinary skill mix, which has been advocated for specialist epilepsy services in learning disability.⁸

Developing the assessment document allowed us to standardise questions asked during the clinic. This led to improvements in clinical documentation.

The introduction of a specific clinic for epilepsy allowed us to identify a list of patients with epilepsy, creating a database for further reference. Whilst drawing up the initial list of patients one person was identified who had been lost to follow up. We also identified two patients who had been erroneously diagnosed with epilepsy; they were not included in the final audit data.

The clinic focused largely on medical issues, e.g. seizure descriptions and matching anti-epileptic medications to seizure type. This however reflects advice given in the NICE guidelines and has been previously shown to be of significance.^{9–11} Increasing the amount of time of each appointment allowed us to explore nursing and psychosocial issues.

Nursing roles within the clinic

Evidence for the effectiveness and role of the epilepsy specialist nurse continues to be debated.^{12–14} Previously the epilepsy specialist nurse had a minor involvement in out patient care, the study allowed her to expand her role, and reflect on the effectiveness of joint working. This was aided by the nurse's in-depth knowledge of epilepsy assessment, management and treatment options.

The inclusion of the epilepsy specialist nurse encouraged exploration of social issues such as travelling abroad, insurance, and quality of life. Other roles included pre consultation assessments and liaison between both the patient and other services to ensure well coordinated care.

As a result of the poor documentation in the initial audit, training deficits were identified. One of the expanded roles of the epilepsy specialist nurse was to develop and deliver a training package to all new medical staff to the trust. She is also available to all medical staff for advice on any relevant issues pertaining to epilepsy care.

We found this an effective use of a scarce resource that led to significant benefits to patients.

Seizure assessment

The use of a thorough approach during the consultation, led to an improvement in seizure descriptions, and a more accurate account of seizure frequency and severity. This highlights the need for professionals to continually ask for confirmation of seizure type, e.g. getting carers to demonstrate the seizures,

as there was a high level of misclassification. Commonly, seizures that were previously described as tonic-clonic and absence seizures were reclassified as complex partial seizures with secondary generalisation.

Re-evaluating seizure assessments allowed the NICE clinic to question and openly discuss symptomatology and the possible reasons for it, 9% of patients seen at the NICE clinic were experiencing seizures whilst previously being identified as seizure free.

This reclassification resulted from witnessing seizures in the NICE clinic and in-depth questioning, which helped differentiate between behavioural disorders and seizure activity. For example, a patient experienced a complex partial seizure during the consultation. The carers attending described the event as a typical behaviour and did not identify it as seizure activity.

Due to poor documentation of seizure descriptions only two seizures could be included from the initial audit when comparing whether seizure type and description matched.

Following the NICE clinic 80% compared to 6% of patients had a name and detailed seizure description. It can be concluded that better seizure assessment led to improved matching between seizure description and documented type, fewer number of patients were classified with multi seizure types, this led to 76% of patients having changes made to seizure classification.

If after the consultation seizure description or differential diagnosis remained unclear further monitoring was requested, e.g. videos. Asking for seizure type and descriptions identified carer's knowledge of epilepsy and highlighted the need for educational input into the recording and monitoring of epilepsy, as well as basic epilepsy awareness training.

Out of the 25 seizures recorded during the NICE clinic all seizure type and descriptions matched. All seizure descriptions also included an assessment of seizure frequency and severity. Anecdotally, we were more likely to receive useful information or documentation of seizures from parents rather than paid carers.

Treatment

The audits showed little difference between medications prescribed in consultation with patient and or carer. Medication was not documented for three patients in the initial audit therefore it cannot be confirmed whether it was discussed. There was an overall improvement in the documentation of medication, and it was more likely to be prescribed

relevant to seizure type. All patients on three or more AED's had a reduction plan after the NICE clinic, 91% compared to 50% of consultations led to changes in the treatment plan.

The use of the baseline tool enabled the clinic to better identify documentation in relation to side effects, benefits and titration rates of medication.

The prescription or use of rescue medication was often not documented in the initial audit. The NICE clinic was more likely to identify whether people had rescue medication prescribed, whether there was a plan in place for its use and whether it had ever been administered. After assessment we either ceased the rescue medication or made a referral to the community nursing team if no care plan was in place.

Risk assessment

During the consultation, a discussion surrounding risk assessment was routine, this was aided by the use of a risk assessment tool. This included those specified by the NICE guidelines in relation to individuals with learning disabilities, which in turn resulted in more appropriate referrals. For example, one person's level of support whilst travelling was increased.

Information sharing

As a general rule the NICE clinic identified that non-paid carers gave a better account of the patient's history, seizure descriptions and current seizure frequency. The appointment letter specifically requested bringing documentation and monitoring forms, sometimes this documentation was not available and when brought it was not always fully completed. In some cases the carers were unfamiliar with the patient and their epilepsy. We witnessed three people have seizures during the consultation, one of the carers present did not identify these events as seizures.

One of the aims of the clinic was to raise awareness of the NICE guidelines. We achieved this in several ways:

- Copies of the NICE guidelines were available for patients, carers and relatives.
- We gave all carers advice about the NICE web site.

In line with the NHS plan and the NICE guidelines, all letters were copied to patients, and where relevant, relatives or carers. All treatment plans were agreed with patients/carers. Unfortunately we did not have resources to use other formats, e.g. audio versions.

Benefits and pitfalls

Setting up the clinic took longer than expected and developing a database of patients with epilepsy is a good idea. The extra time that we had allowed for more in-depth questioning of relatives and carers leading to improved seizure descriptions.

We did not develop a patient, relative or carer service satisfaction questionnaire. This would have proved useful to direct future developments of the clinic. It would have allowed us to better evaluate the pre clinic visits by the epilepsy nurse.

Invitation to community nurses and social workers allowed for a more holistic approach to care and also facilitated our communication with the community team as individual roles in patient care were identified at the clinic. Copying of letters allowed for a more frank discussion of treatment. We did not however amend the GP letters to make them easier to understand to patients. We were available at any time to discuss concerns on receipt of the letter.

All appointment letters included a request to bring relevant documentation. As this sometimes did not happen, we developed a reminder letter requesting specific information, i.e. seizure frequency charts.

One of the benefits was the good working relationship and mutual respect between us. Acknowledging that each individual's knowledge and experience of epilepsy management led to wider discussions, leading to better patient outcomes.

Outcomes

The implementation of NICE guidelines in this study showed improvements to seizure assessments, matching of medication to seizure type, patient care and epilepsy management. Although we accept that we are not comparing individual patient's treatment prior to and after the NICE clinic, we found that:

- 83% compared to 6% of patients had accurate name and detailed seizure descriptions.
- 100% compared to 81% and 57% had recording of seizure frequency and severity.
- 76% of patients had changes made to their seizure diagnosis.
- 91% compared to 50% of consultations led to changes in treatment plans.
- 96% compared to 64% had medication prescribed relevant to their seizure type.
- All patients prescribed 3 or more AED's received a medication reduction plan.
- All patients received an individualised risk assessment compared to 4.5% beforehand and 68% had risks identified.

Conclusions

We showed that it is possible to implement clinical guidelines and that this may lead to improvements in epilepsy care.

To help clarify this, the outcomes of the clinic shall be audited 1 year following its completion. It will examine the implementation of treatment plans, focusing on epilepsy management, medication, seizure descriptions, frequency and severity.

Whilst we focused on people with a learning disability, similar studies may be beneficial in other patient groups.

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