



Audit of healthcare provision for UK prisoners with suspected epilepsy

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Summary

Purpose: To describe the prevalence and nature of epileptic seizure disorders in a typical UK prison and compare the care offered to prisoners to the recommendations of the National Institute for Clinical Excellence (NICE).

Methods: Over a 14-month period, all prisoners identified as having epilepsy were registered by prison primary healthcare services at a category 'C' prison holding 640 male adults. Prison and National Health Service health records were reviewed, prisoners were re-assessed by members of a specialist secondary care service based in the local general hospital NHS.

Results: Twenty-six prisoners were thought to have epilepsy. 61.5% of diagnoses had not been made by epilepsy specialists, 73.1% had uncontrolled seizures, only 19.2% had had computed tomography, none magnetic resonance imaging. At review, 30.8% of prisoners were thought to require neuroimaging, 19.2% cardiac investigations. The diagnosis of epilepsy was confirmed in only 57.9% of those prisoners considered to have the condition by prison healthcare services. 53.8% of those prisoners confirmed as having epilepsy had not had a medical review in the past 12 months; 63.2% required a change in their antiepileptic drugs (AEDs).

Conclusion: Although the prevalence of epilepsy in this prison population appeared high at first sight, a critical review of the diagnoses reduced the difference to the prevalence of epilepsy in the population at large. Fewer prisoners than expected achieved seizure control. Collaboration with specialist epilepsy services was poor.

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There were significant discrepancies between the healthcare provision in prison and the NICE epilepsy guidelines.

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Introduction

The primary purpose of a prison is to detain people denied their liberty by the application of the law. Prisons are not intended to reduce prisoners' access to healthcare. In fact, it is established government policy in the UK that healthcare provision for prisoners should meet the standards developed for the population at large.¹ In the UK the National Institute for Clinical Excellence (NICE) has been charged with developing such standards. In 2004 it published guidelines for the diagnosis and management of the epilepsies in adults in primary and secondary care.² The recommendations in these guidelines are graded according to the level of supporting evidence (see Table 1).

We were concerned about the many barriers, which exist to the provision of optimum epilepsy healthcare in prisons (including the reluctance of professionals to venture into the custodial environment, lack of clear referral routes, and reluctance of hospital-based services to respond to referrals from a prison or to provide outreach services). We undertook this audit to describe the prevalence and nature of seizure disorders in a typical UK prison and to examine how the standards of diagnosis and management of epilepsy in prison compare to the NICE guidelines for this disorder.

Methods

The audit resulted from a collaboration of a Clinical Nurse Specialist (CNS) in Epilepsy based at the local NHS hospital (PT) and a prison nurse based with the client group (JC). The prisoners were identified and

reviewed for the purpose of this audit between June 2004 and August 2005. The audit was approved by South West Staffordshire Primary Trust.

Setting

The audit was carried out in a medium level security (category C) prison, housing 640 sentenced male adults. The prison was split into two distinct units with separate healthcare provision. In line with common prison practice, prisoners were placed in these units depending on their behaviour and/or the nature of their conviction (e.g. those convicted of sexual offences have to be segregated for their own protection). Prison healthcare was fragmented further by separate regimes within individual wings, with resources allocated according to the perceived risk and need of the prisoner group. Healthcare was delivered by one part-time Medical Officer (a General Practitioner), and a small team comprising of a mixture of Health Care Officer's (HCO's, prison officers who have completed a short course in general health care) and Registered Nurses (RN's). There were no inpatient facilities, and healthcare staff were based on the different wings between the hours of 07.30 and 20.45. There was no resident medical cover overnight.

Case identification

During the audit period the treatment sheets of all prisoners passing through the institution were examined for evidence of Anti Epileptic Drug (AED) prescribing. The results of this search were cross-referenced against the Inmate Medical Record (IMR) to ensure the AED prescribing was related to seizure

Table 1 Grading of recommendations by the UK National Institute of Clinical Excellence

Grade	Definition
A	Directly based on category I evidence (meta-analysis of randomized controlled trials (RCTs) or at least one RCT)
B	Directly based on category II evidence (at least one controlled trial without randomization or at least one other quasi-experimental study) or extrapolated from category I evidence
C	Directly based on category III evidence (non-experimental descriptive studies) or extrapolated from category II evidence
D	Directly based on category IV evidence (expert committee reports or clinical experience of respected authorities) or extrapolated from category III evidence
N	Recommendation based on NICE guideline or technology appraisal
GPP	Good practice point based on the clinical experience of the Guideline Development Group

activity rather than other indications (for example to control aggressive behaviour). Prisoners were also included in this audit if they were not taking AEDs but known to have seizures.

Data collection

Data were extracted from the treatment sheets and IMR. All prisoners identified as having a possible seizure disorder were assessed face-to-face by the prison nurse (JC) and (if possible) the Clinical Nurse Specialist in Epilepsy (CNS, PT). The CNS was considered competent in the diagnosis of patients with epilepsy by his National Health Service (NHS) supervisors and routinely diagnoses epilepsy in his NHS role. Information about previous investigations and current medical treatment gathered from prisoners or the IMR were crosschecked against the NHS medical records if available.

Results

Demographic variables

During the course of the audit, the prison’s population fluctuated as prisoners moved around the prison system, or were released back into the community. However, the prevalence of prisoners considered to have epilepsy remained virtually static during the period in which this service audit was undertaken. A ‘snap shot’ of the prison’s population in June 2004

revealed a total of 641 prisoners, of which 13 were considered to have epilepsy and were receiving antiepileptic medication (2%). Over the whole period of the audit 26 prisoners with presumed epilepsy were identified. (see Table 2 for further demographic information). 18/26 (69.2%) were identified because they were taking AEDs, 8/26 (30.8%) because they were known to have seizures although they were untreated. Whereas all of these prisoners were assessed by the prison nurse (JC) only 17/26 (65.4%) were reviewed by the CNS in epilepsy and 1/26 (3.8%) was seen by a Consultant Neurologist. The remaining 8/26 (30.8%) prisoners were not seen by an epilepsy specialist because they were transferred to other prisons (7/26) or escaped (1/26) before a review could be arranged.

34.6% of prisoners considered to have epilepsy were placed under a “basic regime”, which offers only basic privileges such as shorter domestic visits and more limited time out of cells, and resided on the wing with a reputation for managing those with disruptive behaviour. Apart from the restrictions of the basic regime, those prisoners considered to have epilepsy were also placed under ‘epileptic restrictions’, which could include not being allowed to occupy a cell which required walking upstairs (‘locate flat’), or not being allowed to work in particular workshops or the kitchen (‘Labour 2B’). The majority of prisoners considered to have epilepsy were placed under ‘shared cell’ restrictions, which represents a further limitation of potential privileges, as other prisoners who had earned ‘enhanced status’ were invariably accommodated in single cells.

Seizure onset and frequency

7.7% of prisoners reported an age at seizure onset of less than 10 years; 57.7% of 10 to 20; 26.9% of 20 to 30; and 7.7% of more than 30 years. The median reported seizure frequency was 3 per year (range: 1 in 8 years to 96 per year). The distribution of reported seizure frequencies is shown in Fig. 1. 7/26 (26.9%) of

Table 2 Demographic details of prisoners with seizures identified in one UK prison over a 14-month period

	Prisoners identified (N = 26)
Median age (range)	31 (22–49) years
Ethnicity	White 21/26 (81%) Black 3/26 (12%) Asian 2/26 (8%)
Nature of crime	Acquisition 18/26 (69%) Sexual 4/26 (15%) Violence 3/26 (12%) Drugs 1/26 (4%)
Median length of sentence (range)	4.75 (2–9) years
Median number of previous convictions (range)	15 (0–50)
Median number of adjudications (range)	3 (0–21)
Prisoners with security marker	11/26 (42.3%)

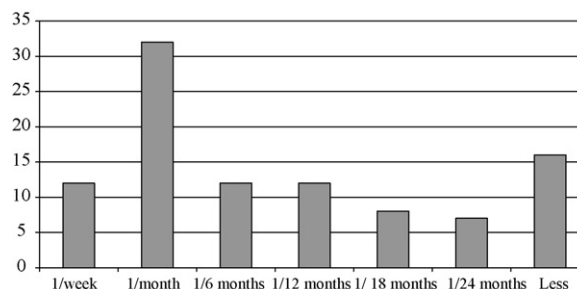


Figure 1 Distribution of seizure frequencies reported by 26 prisoners thought to have epilepsy.

prisoners had been seizure-free for at least 12 months. The seizure frequency of one prisoner was not recorded by the CNS before he escaped from custody, but he had reported to the prison nurse that his seizures were not controlled.

Potential relation to illicit drug use

38.4% of prisoners reported that seizure developed within 12 months of commencing significant substance misuse (usually cocaine and/or alcohol). Illicit drug use often continued. Mandatory Drug Test (MDT) records suggested recent drug use in 23.1% of the prisoners reviewed. Many prisoners also recognized substance abuse as a trigger factor for ongoing seizures.

Investigations

The NICE guidelines suggest timely neuroimaging for all patients who develop epilepsy as adults, especially when there are seizures with focal features or when seizures continue despite medication (unless the EEG has confirmed a diagnosis of idiopathic generalized epilepsy, recommendation category C). They describe magnetic resonance imaging (MRI) as the imaging investigation of choice (category C). Only 5/26 (19.2%) of prisoners considered to have epilepsy by the prison medical officer had undergone a CT head scan, and this had invariably happened prior to custody. None of the prisoners considered to have epilepsy had been investigated with cranial MRI. Based on the NICE guidelines neuroimaging was required in 30.8% of prisoners.

The NICE guidelines do not recommend that all patients with possible epilepsy should have an EEG.

However, the guidelines state that EEG examinations can be used to support the diagnosis of epilepsy in adults in whom the clinical history suggests it, to help determine seizure type and syndrome and to assess seizure recurrence risk after a single unprovoked seizure (recommendation category C). Only 50% of those prisoners considered to have epilepsy by prison primary healthcare services had had an EEG. Where EEG had been undertaken, the results were interpreted by the referring clinician rather than an epilepsy expert.

Diagnosis

According to the NICE guidelines the diagnosis of epilepsy should always be made by an epilepsy specialist (recommendation category C), and seizures and seizure syndrome should be classified

using a multiaxial diagnostic scheme (category D). In the prisoners, only 10/26 (38%) of the diagnoses of epilepsy had been made by specialists. No syndromic diagnoses were recorded.

The diagnosis was reviewed in 19/26 (73.1%) prisoners who were available for face-to-face assessment by an epilepsy specialist. Only 11/19 (57.9%) were thought to have definite epilepsy. The diagnosis was considered doubtful in the remaining 8/19 (42.1%): 4/19 (21.1%) were thought to have non-epileptic seizures, 2/19 (10.5%) recurrent syncope, one was thought to have panic attacks, and one drug-induced, provoked seizures.

Developmental history and psychiatric comorbidity

12/26 (46.2%) prisoners with seizures grew up in care homes, an unstable or abusive family environment. The records of only 3/26 (11.5%) of prisoners with seizures and 1/11 (9.1%) of patients with confirmed epilepsy made no reference to psychiatric symptoms. The commonest problems in prisoners with epilepsy were drug or alcohol addiction (5/11, 45.5%) and deliberate self-harm or parasuicide (3/11, 27.3%).

Treatment

According to the NICE guidelines antiepileptic drug treatment should be initiated by an epilepsy specialist who should also provide a plan for continuation of therapy and be consulted about medication withdrawal (recommendation category GPP). They should be provided with an accessible point of contact with the specialist services (category GPP). None of the prisoners identified (including those who had seen specialists in the past) had access to specialist services at the time of the audit. Generally prisoners were prescribed monotherapy, but 2/26 (7.7%) received a combination of two or more AEDs. The AEDs used included carbamazepine (14 prisoners, median dose 400 mg daily, range 200–800 mg), lamotrigine (3 prisoners, median dose 200 mg daily, range 50–400 mg), phenytoin (3 prisoners, 300 mg daily) or sodium valproate (2 prisoners, 900, 1000 mg daily). The audit found that 7/26 (26.9%) prisoners were receiving AED treatment in surprisingly low doses despite ongoing seizures (≤ 200 mg carbamazepine/day, ≤ 50 mg lamotrigine/day). There was no evidence that treatment plans had been discussed with epilepsy specialists. Epilepsy specialist review resulted in recommended treatment changes in 12/19 (63.2%) prisoners (withdrawal 4/19, medication increase 4/19, medication change 4/19). Prescribing errors were found, for

example several prisoners initially prescribed "Tegretol Retard" had their prescription changed over time to read 'Tegretol' and were receiving standard formulation carbamazepine preparations twice a day.

According to the NICE guidelines patients should receive appropriate information about all aspects of epilepsy, which should be maintained through structured self-management, plans (category A). Although most prisoners were self-medicating, there was no evidence that prisoners had been educated about these drugs or had formal management plans. Titration programmes were poorly understood among prison healthcare staff. AEDs were dispensed to prisoners weekly, and titration was often thwarted by the reluctance of healthcare staff to dispense AEDs before the next weekly collection date because they realised that AEDs were being traded illegally within the prison. Prisoners had no means of safely storing their medication in a secure cabinet.

Although (with the exception of phenytoin) the NICE guidelines do not recommend this practice (recommendation category D), in prisoners dosages were often adjusted according to blood levels, rather than in response to clinical symptoms. Intramuscular diazepam was used for status epilepticus, but there was no protocol for management of status until it was introduced by the investigating team. Lack of knowledge and training in first aid treatment of seizures was the rule, and many prisoners expressed anxiety about how their seizures would be managed, especially at night when the prison was placed in patrol state with limited staff observation.

The NICE guidelines recommend a regular structured review of epilepsy treatment at least once per year and referral to specialist care if epilepsy is inadequately controlled (category D). 14/26 (53.8%) of prisoners had not had an epilepsy or treatment review in the past 12 months, with the majority of these having had no review in the past 10 years. When they were reviewed in for this project, a change of medication was suggested in 12/26 (46.2%) of prisoners with epilepsy. No prisoners had been assessed for epilepsy surgery.

Advice and information

None of the prisoners with epilepsy were given information concerning their condition, or safety issues. Internet access was not available and no patient information leaflets were being made available. None of the prisoners had been given advice concerning Sudden Unexpected Death in Epilepsy (SUDEP), even though the prison had experienced a death in custody related to epilepsy

in recent years. 17/26 (65.4%) of the prisoners with epilepsy had not been advised of driving regulations in preparation for their release back into society.

Discussion

Two percent of the prison population had a diagnosis of epilepsy or were receiving AEDs for this condition. This suggests that the prevalence of epilepsy amongst prisoner was increased compared to the established prevalence of 5–10 per 1000 in the general population.^{3,4} This result would be in keeping with previous studies.^{5–11} For instance, one study in the UK estimated a prevalence of 7.1/1000 in prisoners and cited a prevalence of 4.5/1000 in the general population.⁷ However, face-to-face review by an epilepsy specialist nurse with recognized competence in the diagnosis of seizure disorders suggested that the diagnosis of epilepsy may have been applied inappropriately in 57.9% of prisoners. Although our case ascertainment method would have failed to identify prisoners with epilepsy who were not taking medication and had not disclosed the diagnosis, this indicates that the true prevalence of epilepsy in the prison may be lower than previously reported and similar to that in the population at large. This conclusion matches the finding of a meta-analysis of studies describing the prevalence of epilepsy amongst prisoners which only included studies involving a face-to-face assessment of individual prisoners.¹²

The seizure frequency distribution found in the described group of prisoners suggested that seizures were more poorly controlled than in community-based populations of people with epilepsy. Whereas seizures were in remission in only 26.9% of prisoners the equivalent figures from two UK-based primary care studies were 53%¹³ and 61%¹⁴, respectively. Over the longer term one would expect over 60% of patients to stop having seizures with modern antiepileptic drug treatment.¹⁵ The two most obvious reasons for the low rates of prisoners achieving seizure control evident from our audit were that diagnoses were inaccurate in a high number of prisoners and that antiepileptic drugs were used in surprisingly low doses in many cases.

Our review of the available medical records suggested that prisoners often had a traumatic developmental background and (in keeping with a previous study¹⁶) increased rates of psychiatric co-morbidity. For instance, in one recent study including a group of patients with epilepsy 39% had no co-morbid psychiatric diagnosis,¹⁷ whereas the corresponding figure in this study is less than

10%. The lifetime risk of substance abuse in patients with epilepsy in another study was 20.1%,¹⁸ whereas it was 45.5% here.

This audit suggests that the medical service currently offered to prisoners with epilepsy in the UK falls short of national treatment guidelines in many areas although it is government policy that prisoners should receive the same level of healthcare as members of the public at large. The discrepancies between the NICE guidelines on the management of the epilepsies and the health care received by prisoners affected all aspects of medical care from investigations, diagnosis and access to specialist advice to treatment plans and access to information about epilepsy.²

The UK government has been concerned about inequalities between healthcare in prisons and the community for a long time. Recent reforms have addressed this problem by integrating the Prison Medical Service into the National Health Service (NHS).¹⁹ In 2002, this strategy culminated in the decision to transfer the budgetary responsibility for prison health from the Prison Service to the Department of Health. Since April 2006 full commissioning responsibility has been devolved to local Primary Care Trusts (PCTs).²⁰ Our audit suggests that the implementation of the NICE guidelines in prisons will be a particularly urgent and difficult task for PCTs.

One important challenge will be the development of a better working relationship between prison health care staff and secondary care. The NICE guidelines recognise that the involvement of an epilepsy specialist is important for the diagnosis of epilepsy because a range of studies had demonstrated misdiagnosis rates of one in four patients thought to have epilepsy in primary care,²¹ or referred to a secondary care service because of "refractory epilepsy".²² Whilst it is recognised that there is a prevalent population of patients with epilepsy in the UK who have never seen an epilepsy specialist, the proportion of prisoners with suspected epilepsy who had never seen an epilepsy expert (61.5%) even exceeded the 55% of people with epilepsy in a recent UK-based rural community study who had never been seen in secondary care.¹⁴ The NICE guidelines also suggest that specialists should be involved in starting, planning and withdrawing antiepileptic drug treatment. To improve the quality of diagnosis and treatment of epilepsy in prisons, specialist services will have establish closer working relationships with prison health care staff, consider visiting prisons to ensure that prisoners can be interviewed in an environment where confidentiality can be assured. It is unlikely that prisoners would volunteer a perceived connection of seizures and ongoing substance abuse if they were ques-

tioned about this in the company of prison officers escorting them to outpatient appointments—it should be noted that the high rate of alcohol and substance abuse in prisoners with epilepsy has also been described by other authors.^{23,24} It is also unlikely that seizure witnesses could be questioned outside prison. Given the considerable cost of sending a prisoner to a hospital outpatient appointment (approximately £250.00 plus the cost of the consultation) an additional investment in specialist outreach services covering prisons may even be cost-effective.

One particularly urgent area requiring collaboration of prison and specialist medical staff is the improvement of the drug treatment of epilepsy in prison. In an environment where AEDs have significant illicit trading value, interpretation of blood levels to check concordance may be useful. However, prison medical staff should realise that the adjustment of medication based on the measured values *can be dangerous and* does not reflect current best practice.² AEDs are frequently prescribed in low doses, which are not escalated if seizures continued. Rescue medication is not used. The authors recognise that rescue medication presents problems in an environment where drugs are commonly abused. Nevertheless, the prison authorities have a duty of care and need to ensure that prisoners are safe whilst they are in custody. This means that a system of observation needs to be in place, which ensures that prolonged epileptic seizures are noticed, and that there is access to appropriate medical help and emergency medication if required.

Much of the input of specialist staff should be educational. The interaction with prison staff and prisoners during this project revealed that there was a need to deliver training to the prisoner as a patient, prison nursing staff, prison officers as well as the prisoner peer group as a whole. First aid training and awareness education should be offered to cell mates of prisoners with epilepsy. Such measures could in some part confront the stigma of epilepsy that remains entrenched within the prison environment.

Prior to this project, social and lifestyle issues related to epilepsy had not been critically reviewed in the prison where the audit was undertaken. The stigma of the condition was highlighted by the use of the label "epileptic" being written on role boards and added to cell door cards identifying that the occupier had epilepsy. Issuing "identity cards" has helped in this regard. Prisoners with epilepsy had restrictions placed on their living arrangements, and invariably had to share a cell and use the bottom bunk irrespective of their seizure frequency, thus eroding their perceived status. Information leaflets

on epilepsy are geared to life in the community at liberty and were noted to have limited relevance in the custodial setting, especially where reading skills are limited. The authors understand that Epilepsy Action (a leading UK-based epilepsy charity) is currently in the process of developing better-targeted information.

Conclusion

Whilst the authors accept that their results are based on a relatively small audit in a single prison, they have no reason to believe that the health provisions in the institution where the audit was undertaken are particularly poor. The findings place an onus on other institutions to check that their services are superior. Improvements in the prison health service are essential if prisons take their rehabilitative role seriously. Although some improvements may be made through the education of existing staff and more efficient use of current clinical services, it is likely that significant progress will require additional funding. A period in prison should not be a health hazard for people with epilepsy but an opportunity to break out of a cycle of seizures, stigma, low self-esteem, unemployment, substance abuse and crime.

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