

EPILEPSY IN A MENTAL HANDICAP HOSPITAL: A SURVEY REPORT

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Introduction

People with severe mental handicap suffer more commonly from epilepsy (Corbett, 1993) and this dual disadvantage has considerable implications in planning services for this group of people. Epilepsy can cause additional stress to the carers and uncontrolled epilepsy could become an important factor in the failure of community care in some individuals. Few studies have investigated the prevalence of epilepsy in long-stay mental handicap institutions but a recent study (Sachdev, 1991) reported a prevalence of 26% in a long stay mental handicap hospital.

The long term use of antiepileptic drugs (AED) in people with mental handicap continues to be a source of concern. Chronic AED medication without regular review and inappropriate

polypharmacy can lead to behavioural disorders and cognitive impairment (Shorvon., 1990; Trimble, 1983). It has been reported that a system of periodic review of AED medication by a group of professionals (including the hospital pharmacist) in a mental handicap hospital reduced polypharmacy and also led to a significant reduction in the frequency of seizures in some residents who had chronic epilepsy (Collacott *et al.*, 1989).

This study investigated the prevalence and type of epilepsy, the use of electro-encephalogram (EEG) investigation and assessment of serum AED in the clinical management of epilepsy in a mental handicap hospital in the West Midlands.

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Method

The hospital has a catchment area population of about 700,000 and at the time of study (1-1-1991 to 31-12-1991) there were 308 long stay residents. Residents who had a history of epilepsy were identified and information relating to age, sex, degree of mental handicap, type and frequency of epilepsy, type of AED medication, whether EEG and estimation of serum AED levels were performed was collected from the medical case notes.

Results

Of the 308 residents 104 (33.8%) had epilepsy. Two residents were excluded from further study as one of them was a short stay resident and the other died during the study period. The mean age of the remaining 102 residents was 41.8 years (age range 18 to 82 years, SD 12.95). There were 58 (56.9%) males and 44 (43.1%) females. Ninety two (90.2%) residents had an IQ less than 50.

A total of 1896 seizures were recorded (TABLE I). Seventy three (71.6%) residents had one or more seizures during the study period. Thirty-two (31.4%) residents had 1 to 5 seizures, 14 (13.7%) residents had 6 to 10 seizures and 27 (26.5%) residents had more than 10 seizures. Twenty-one (20.6%) residents had no recorded seizures during the study year and there were inadequate epilepsy records in the case notes of 8 (7.8%) residents.

Eight classes of AED were prescribed (TABLE II) and 80% of them were given for more than one year. More than 50% of the residents were given carbamazepine and/or sodium valproate. Forty-six residents (45.1%) were on only one AED medication. Thirty-five (34.3%) residents were on 2 drugs and 19 (18.6%) residents were on 3 or more drugs. Two (2%) residents were on no medication for their epilepsy.

During the study period serum AED monitoring was performed on 65 occasions in 43 (42.2%) residents. The reasons for serum assays were "routine" on 17 (26.2%) occasions, suspicion of

TABLE I
Type and frequency of seizures recorded

Type of Epilepsy		Cases	
		Number	Percentage
Generalized	tonic/clonic	1113	58.7
	absence	305	16.09
	myoclonic	154	8.12
Partial	elementary	29	1.53
	complex	266	14.03
Unclassified	—	29	1.53
		1896	100.00

toxicity on 14 (21.5%) and increased seizure frequency on 9 (13.8%) occasions. In 25 (38.5%) of the requests for the assay no specific reason was given. The results of the assay led to a subsequent change in the medication in only 13 (20%) of the requests. Only 3 residents had an EEG investigation during the study period.

Discussion

The 33.8% prevalence of epilepsy in this study is higher than that of 26% reported by Sachdev (1991). This difference may, in part, be due to the inherent difficulty in resettling those with chronic epilepsy. A male preponderance in the number of those with epilepsy (male 57%; female 43%) in our study is consistent with the reports of Collacott *et al.* (1989) and Sachdev (1991).

About 21% of the residents had no seizures during the previous year and this suggests that a further review, with management plans for possible reduction

and eventual withdrawal of AED medication in some of them would be an appropriate clinical management for their epilepsy. Seven percent of the case notes had inadequate epilepsy records and this highlights the need for regular monitoring and recording of seizures. The process of identification of the type of epilepsy from the descriptions given in the case notes proved to be difficult although tonic-clonic epilepsy was thought to occur in 59% and absence (petit-mal) epilepsy in 16% of the residents. Identification of tonic-clonic movements by the ward staff is probably more reliable than other types of movements or behaviours that are associated with an ictal event.

Carbamazepine, sodium valproate and clobazam were the most commonly (>75%) used drugs (TABLE II). Also, both older class (phenobarbitone) and relatively newer class of drugs, c.g. vigabatrin, were used. The rate of polypharmacy in this study was 18.6% (3 or more drugs) compared to that of 12% reported by Collacott *et al.* (1989). In

TABLE II
Anticonvulsants and number of prescriptions recorded

Anticonvulsant	Prescriptions	
	Number	Percentage
Carbamazepine	59	33.7
Sodium valproate	43	24.6
Clobazam	32	18.3
Phenytoin	17	9.7
Primidone	11	6.3
Phenobarbitone	9	5.1
Vigabatrin	3	1.7
Ethosuximide	1	0.6
Total	175	100.0

some people with epilepsy AED polypharmacy can lead to an increase in the frequency of epilepsy and chronic toxic effects could alter the arousal levels leading to cognitive impairment (Shorvon, 1980; Trimble, 1983). Although this study emphasizes the need for a regular review of polypharmacy, in most individual cases the reduction requires careful evaluation based on individual case histories as ill considered changes can also lead to increase in fit frequency (Ferngren *et al.*, 1991).

Only 3 EEGs were performed during the study period and this reflects similar findings in previous studies by Sachdev (1991) and Deb and Hunter (1991). Two EEG investigations were conducted in residents who had epileptic seizures without a previous history and in one resident there was an increase in fit frequency. All the 3 recordings confirmed an abnormal electrical activity. There is no clinical consensus as to how often should EEGs be performed in individuals with mental handicap and associated epilepsy.

Forty two percent of the residents had serum AED assays during the study period. This invites the question as to how frequently should the serum drug levels be carried out. It is pertinent to note that expert opinion on this aspect of management is divided and although low rates of serum monitoring have been criticized no firm guidelines indicating an acceptable standard of good practice has been offered (Sachdev, 1991). Suspected drug toxicity, reduced seizure control and where compliance is suspect could form indications for monitoring the

serum drug levels. Serum AED monitoring is of some value in phenytoin and carbamazepine usage but of little clinical value in benzodiazepine and sodium valproate. Additional problems in the management of epilepsy in people with mental handicap includes difficulty in detecting the presence of side-effects. Also, the procedure of periodic venesection to obtain samples of venous blood could become a very traumatic, and in some residents with mental handicap a major event.

Collacott *et al.* (1989) have shown that regular clinical and therapeutic monitoring of epilepsy by a group of professionals in a mental handicap unit can lead to significant improvements in the care of those with chronic epilepsy. Such special interest groups can be initially formed in the existing mental handicap hospitals and later the cumulative expertise can be extended to those living in the community. In addition to medical and pharmacological therapies interventions such as behavioural management for epilepsy, with special attention to the quality of life of these disabled people (Mittler, 1984) can be provided by these groups.

Implications for care in the community

There are several problems in the community management of people who suffer from epilepsy. Parents of people with learning disability experience mixed feelings when they interact with a medical professional, such as for example a

doctor, more so when they have to deal with the reality of their sibling's disability (Quine and Phal, 1987). In addition, when an added handicap such as epilepsy becomes intractable the emotional adjustment can be a very traumatic process (Hollins, 1988). It follows, therefore, that every effort must be made to reduce the chronicity of epilepsy in those living with their parents and carers.

During the late sixties community services for people with epilepsy were examined by the Reid Committee (Reid, 1969) and the establishment of multidisciplinary teams with the family doctor, consultant physician, a social worker, a clinical psychologist, a local authority staff and a disability officer as members of the team was suggested. This led to the establishment of specialist residential centres for the management of intractable epilepsy but no equivalent service was established in the community.

Later, in 1984, the DHSS (1984) made specific recommendations with regard to the establishment of epilepsy clinics, similar in its remit and function to those providing long term follow-up care to people with a chronic medical illness, such as, for example, diabetic disorders. However, these epilepsy clinics were run as out patient clinics based in the medical model of care, and in practice were focused on aspects of medical investigations, episode monitoring and evaluation of drug therapies. Clearly, aspects of social care (Arrangio, 1978), psychological aspects of chronic disability (Cofield and Austin, 1984) and carers' problems were of secondary importance to the role of these clinics. Community health

services, as suggested in the Cumberland report (DHSS, 1986), focused on the feasibility of multiprofessional community management of people with chronic medical illnesses. In keeping with the current approach to management of chronic epilepsy and supporting people with intractable epilepsy living in the community the above mentioned models of care for most people with a learning disability are unsatisfactory. Only 10% of people with epilepsy have regular contact with hospital outpatient departments, and most others obtain such a follow-up care from their primary health care team (E.P.A., 1978; Goodridge and Shorvon, 1983; Hopkins and Scambler, 1977). Although similar figures for people with learning disability who suffer from epilepsy are not available it is unlikely that such figures could be dissimilar. Furthermore, as people with learning disability are resettled in the community follow-up arrangement for their specialist needs will form part of the family practitioner's responsibility. A seamless service where the person with epilepsy is not disadvantaged is one that incorporates a greater role for local community teams with provision for specialist nurses to monitor long term follow-up and organise relevant services as and when required (Bicknell, 1983).

Summary

Case notes of 308 longstay residents of a mental handicap hospital were studied during 1992 and the details of epilepsy management for 102 (33%)

residents were noted. There were 58 (57%) males and 44 (43%) were females, and 90% of them had an IQ less than 50. A total of 1986 seizures (83% generalised, 15.5% partial and 1.5% unclassified) were recorded. Seventy-two percent of the residents had one or more seizures and 26.5% had more than 10 seizures. Eight types of anti-epileptic drugs were used and only 45% were on monotherapy. Serum drug assay was done on 65 occasions in 42% of the residents and only 3 EEGs were performed during the study year. It is suggested that periodic review of epilepsy management by a specialist multiprofessional group could lead to reduced polypharmacy, better control of epilepsy and enhanced quality of life of longstay residents who have chronic epilepsy.

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