

Epilepsy in the mentally handicapped: a hospital survey

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A survey of the medical management of 75 mentally handicapped in-patients with epilepsy was carried out between June and December 1991. The study focused on the number and type of anti-epileptic drugs used, the frequency of monitoring of serum anti-epileptic drug levels and the nature and frequency of other blood tests carried out. Quality standards were then agreed and the survey repeated a year later. The results show that the agreed standards were generally achieved, although a large number of patients continued to receive more than one type of anti-epileptic drug.

Coldeast Hospital, which has 198 patients, provides in-patient facilities for the Mental Handicap Division of the Portsmouth and South East Hampshire Health Authority. It serves a population of 510,000.

The study

The aim of the surveys, which formed part of the hospital's medical audit, was to obtain an accurate picture of the current medical management of those patients in the hospital with epilepsy, with the intention of improving this over a period of time. The first survey was conducted between June and December 1991. It included those who had had seizures in the previous three years or who were on anti-epileptic drugs prescribed for that reason. In total, 75 patients were studied (37 male and 38 female). Three have since died, but were included in the analysis. The study involved the use of case-notes, drug prescription cards and fit recording sheets. Following the first survey, recommendations for clinical practice were agreed.

The second survey covered the period between June and December 1992. Seventy-two patients from the first survey were studied and there had been two further deaths in this group. The second analysis, therefore, involved 70 patients, three of whom were no longer receiving anti-epileptic medication.

The first survey

The age of the patients ranged from 24 years to 83 years, with a mean of 42.5 years and a median

of 38 years. It was not possible to determine accurately the age of onset of epilepsy in 45% of the patients. Of the remaining patients, about half started having fits before the age of 5 years.

The degree of handicap was defined according to DSM-III-R criteria, although IQ measurements were not available for all patients. The majority (72%) were severely handicapped, 12% were moderately handicapped and approximately equal numbers were either mildly or profoundly handicapped (9% and 7% respectively).

An attempt was made to classify the various types of seizures that the patients suffered. This was not always easy because clinical manifestations were sometimes suppressed by the drugs used. The classification was based on the observations of the nursing staff. Fifty had generalised tonic-clonic seizures; of the remainder, one had temporal lobe epilepsy, one had focal seizures, two had absence seizures and 21 had more than one type of seizure. A retrospective examination of the case-notes revealed that in 53% of the patients the diagnosis of epilepsy had been made on clinical grounds. Of those investigated, about two-thirds had had an EEG. There were two patients whose seizures started in adulthood and both these patients had cranial CT scans. Sixty per cent of the group had on average up to two fits per month; 16% had had between five and ten fits and 8% of the group had in excess of ten fits each month. Additionally five had had no fits in the previous year, three in the previous two years and nine patients in the previous three years. The annual incidence of episodes of *status epilepticus* was about 6%.

The anti-epileptic drugs used and the number of patients receiving each drug were: carbamazepine, 53; sodium valproate, 53; phenytoin, 12; clobazam, 11; barbiturates, 5; and vigabatrin, 3.

Forty-one per cent were on monotherapy and 39% were on two anti-epileptic drugs; 20% received three or more drugs.

Serum anti-epileptic drug levels had never been estimated in the last three years in 23% of the group. Twenty-five per cent of the patients had had these levels monitored annually and 41% had them monitored at least once in the

same period. Folate levels had been measured in only 4%. In the year preceding the analysis, thyroid function had been measured in 40%, serum calcium in 48% and urea and electrolytes in 60%. Forty-four per cent had had a full blood count and 56% had had their alkaline phosphatase measured. There was no correlation between the degree of handicap and the frequency of fits or between the fit frequency and the number of drugs prescribed.

Recommendations The following recommendations for clinical practice were agreed:

- (a) to reduce the number of patients receiving two or more drugs
- (b) to gradually discontinue the use of phenytoin and barbiturates in favour of drugs with fewer side-effects
- (c) those who had not had any fits for three years were to be weaned off their medication
- (d) to measure folate levels, thyroid function, serum calcium levels, alkaline phosphatase levels and obtain a full blood count in all patients at least annually.

The second survey

The findings of the second survey are reported in relation to the recommendations that emerged after the first survey.

- (a) Forty-three per cent of the patients continued to receive monotherapy. The number of patients receiving two drugs fell from 39% to 23%. There was, however, an increase of 14% in the number of patients receiving three or more drugs. Most of these patients were already on two anti-convulsants and new drugs, namely vigabatrin in nine patients and lamotrigine in 13 patients had been added to the treatment regime.
- (b) The number of patients on phenytoin dropped from 12 to seven and only one patient was on a barbiturate (primidone).
- (c) Of the nine patients who had not had fits for three years or longer, three were now off anti-epileptic medication altogether and five patients were in the process of being weaned off their medication. In one patient, whose medication had been discontinued, carbamazepine had to be restarted because of the recurrence of fits.
- (d) In 1992, folate levels had been measured in 58% of the patients, thyroid function in 84%, serum calcium levels in 89%, alkaline phosphatase levels in 89% and a full blood count obtained in 92%.

All the folate levels measured were normal. The following biochemical abnormalities were discovered: hyponatraemia, 6 patients; hypocalcaemia, 8 patients; hypoalbuminaemia, 7 patients; hypothyroidism, 8 patients; anaemia, 1 patient; and raised alkaline phosphatase, 13 patients.

Comment

Most surveys of epileptic populations have been carried out in general practice, usually on those of normal intelligence and there is a paucity of surveys of in-patients who are mentally handicapped. Although both groups are not strictly comparable, some general points can be made. Presley (1989) carried out an audit of epilepsy in general practice and observed 87% of his patients had had EEGs, compared with only 33% in our survey. This may be because the association between epilepsy and mental handicap is well recognised and investigations may have seemed unnecessary. It has been our experience that conventional EEGs are sometimes difficult to carry out on our patients and often were not very helpful for diagnosis. Both our hospital group, the general practice group studied by Hall & Ross (1986) and the hospital sample reported by Fischbacher (1982) appear to be comparable in terms of the prevalent types of epilepsy. We found that 67% of our patients had generalised tonic-clonic seizures, compared with 69% in both the other groups.

Hartropp (1987) and Presley (1989) reported that 45% of their patients were on either sodium valproate or carbamazepine. In the Mersey region in 1989, 31% were on carbamazepine, 30.5% were on phenytoin, 18% were on sodium valproate and 15.7% were on barbiturates (cited in Pirmohamed, 1990). In our group, 71% were on either carbamazepine or sodium valproate, reflecting their greater use in a hospital setting. Only 7% were on barbiturates, compared with 35% and 55% in the two general practice groups.

The case for reducing the number of anti-epileptic drugs that an individual receives is unquestionable. Gunnaway & Mawer (1981) point out that "many poorly controlled epileptic patients gain little extra benefit from multiple drug therapy" and Brodie (1990) emphasises that the "realisation that anti-convulsant polypharmacy confers no benefit over monotherapy in about 90% of epileptic patients must be regarded as a conceptual breakthrough". Fischbacher (1982) in his study of the withdrawal of anti-epileptic medication in a group of mentally handicapped patients observes that "despite reduction in total drug intake, seizures have not increased in the long term and behavioural score improvements suggest that these patients are more comfortable".

There is, however, no established 'target figure' for monotherapy in mentally handicapped epileptic patients. Both our surveys suggest that more can be done to reduce the number of drugs that each patient receives. The problem with the newer drugs, that are marketed as 'adjuncts', is that it can take some time to evaluate the effectiveness of the new drug. There can, therefore, be a delay in weaning such patients off their previous medication, so that for a period of time they receive three anti-epileptic drugs.

The second survey shows an encouraging trend with the reduction in the use of phenytoin and the barbituates.

Not surprisingly, serum levels of anti-epileptic drugs are monitored much less frequently in general practice. Of the patients studied by Hartropp (1987) 21% had had drugs levels recorded in a five year period. This figure is comparable to the number of our hospital patients who had *not* had drugs levels recorded in a three year period.

Pellock & Wilmore (1991) comment that blood monitoring in otherwise healthy and asymptomatic patients receiving anti-epileptic drugs is not necessary. However, they also observe that "patients unable to communicate or without any advocate must be managed differently. Although data is not available, we recommend blood monitoring on an annual basis for multiply handicapped institutionalised patients. Such monitoring should minimally include basic haematology and chemistry".

The blood monitoring undertaken after the first survey was, by any standard, very thorough.

There were, however, relatively few abnormalities discovered by this general screening. Most of the 'abnormalities' were biochemical in nature, with values just outside the 'normal' reference range. There was little in the way of clinical symptoms and signs and, apart from the use of thyroxine and the investigation of the single case of iron-deficiency anaemia, none of the 'abnormalities' required any treatment.

Such monitoring entails considerable expenditure and, on the basis of this survey, we feel that there is little justification for annual monitoring in the mentally handicapped.

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Guide for contributors to the Audit section

Audit should be a circular process. Standards are agreed, a service is surveyed against the standards, a strategy is proposed to improve quality and the service is resurveyed to assess change. The strategies which produce change in one place will often be applicable to services elsewhere. The publication of an audit should therefore contribute to the general improvement of services.

By contrast, a survey of a service frequently produces results which are specific to that place and reflect its geographical and social situation and the local provision of services. While the results may be of great interest locally, they are not applicable elsewhere.

The *Psychiatric Bulletin* welcomes papers describing a completed audit cycle for publication in the Audit section. Simple surveys of services are not acceptable.