

Cross sectional study of reporting of epileptic seizures to general practitioners

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Abstract

Objective Comparison of reporting of recent epileptic seizures by patients to a doctor and anonymously.

Design Cross sectional study of patients with epilepsy by comparison of paired questionnaires.

Setting Rural and urban general practices in Norfolk.

Participants 122 patients aged over 16 years and able to self complete a questionnaire who were recruited by 31 general practitioners when attending for review of their epilepsy.

Main outcome measure The difference in reported occurrence of seizure to general practitioners and in a linked anonymous questionnaire.

Results 18 patients failed to report a seizure in the past year to their general practitioner (uncontrolled epilepsy). 40% (24/60) of people with epilepsy who anonymously reported a seizure in the past year held a driving licence, but only six revealed this to their general practitioner. The unemployment rate was 34%, substantially higher than the 9% in the general population. Measures of anxiety, depression, and stigmatisation were higher in patients with uncontrolled epilepsy.

Conclusions A significant proportion of patients with epilepsy underreport their seizures. Recognition of underreporting is important if patients are to benefit from adequate and appropriate treatment. General practitioners' ability to treat epilepsy is hampered by their role in regulating the rights of epileptic patients to hold a driving licence or access certain occupations.

Introduction

Epilepsy is the most common neurological condition encountered in primary health care in the United Kingdom.^{1 2} General practitioners have assumed much of the responsibility for the continuing management of this condition.³ As the lifetime prevalence of this condition is 2-5% of the population, a general practitioner will care for about 10 patients receiving treatment but will have another 15-25 patients who have had seizures in the past but are no longer receiving treatment.²

A key aspect of monitoring patients with epilepsy is the reporting of seizures to their doctor. This information is used to determine the most appropriate

antiepileptic drug and its dose and is also the basis of advice on lifestyle—for example, driving, employment, and leisure activities. It is therefore unsurprising that several researchers have suggested that seizures—and even the diagnosis of epilepsy—might be concealed. Van der Lugt, for example, reported that only a small proportion of people disqualified from military service because of epilepsy reported their epilepsy when applying for a driving licence.⁴ Taylor et al said that a “considerable proportion of patients may continue to drive illegally.”⁵ Moreover, Hopkins and Scambler reported that 12 (19%) out of 62 subjects ineligible to hold a UK driving licence because of uncontrolled epilepsy were driving, in two cases without a licence.⁶ Similar problems have been found in other countries. A study in the United States found that 28% of drivers with epilepsy would not inform their doctor if they had a seizure,⁷ and an assessment of notification to the driver licensing authorities in Australia asserted that: “patients with epilepsy withhold the diagnosis from the authorities, and worse, may withhold information about the occurrence of seizures from their advising doctors.”⁸

Concealment from employers has also been reported. In a study in the United Kingdom 53% of people with epilepsy and in employment would choose concealment as a strategy.⁹ Scheinder and Conrad identified concealment as one of several processes by which individuals manage their epilepsy.¹⁰ In a study of patients' reactions to fictional situations, Tröster found that disclosure of epilepsy depended on the perceived risk of detection and the anticipated consequences of disclosure; about 30% of patients would never reveal the diagnosis whatever the situation.¹¹

These studies suggest that the concealment of seizures or epilepsy is common and that this is likely to compromise the care of epileptic patients. However, no studies have attempted to quantify the extent to which seizures are concealed. We compared the reported seizures from two questionnaires completed by the same patient, one administered by their general practitioner and one self completed anonymously.

Participants and methods

This was a general practice based cross sectional study into the reporting of seizures to a patient's doctor and therefore removes the bias of other hospital clinic based studies. Two linked questionnaires were

Table 1 Numbers of patient reporting seizures in past 12 months to their general practitioner and anonymously*

Anonymously	General practitioner		Total
	Yes	No	
Yes	42	18	60
No	1	50	51
Total	43	68	111

*McNemar's test for comparison of paired seizure data $\chi^2=13.47$, $P<0.001$. Comparison of proportions=0.162 (95% confidence interval 0.095 to 0.228).

designed to examine expected differences in the reporting of seizures. The first questionnaire was completed by the general practitioner with the patient during a routine consultation. The second questionnaire was sent to the patient two weeks after the initial consultation. At this point the first questionnaire was anonymised and linked to the second questionnaire by a unique number.

The first questionnaire investigated patient characteristics: age, sex, socioeconomic group, and current occupational status and, in addition, information on type of epilepsy, date of diagnosis, treatment, and the date and time (day or night) of last seizure. The second, anonymous, questionnaire was identical to the first apart from the addition of the hospital anxiety and depression scale¹² together with a measure of perceived stigma.¹³ The hospital anxiety and depression scale has been shown to be a sensitive and specific screening tool for mood disorders in patients with somatic illnesses. Scores of 8 or above were taken as predictive of depression or anxiety.¹² Perceived stigma was measured as the positive response to one or more questions asking whether other people were uncomfortable with them, treated them as inferior, or preferred to avoid them.¹³

On the basis of an unpublished audit of practice data from 1994-5 we calculated that the sample size necessary to detect a difference in the reported seizure rates at 5% significance levels and 90% power was at least 85. General practitioners were recruited from Norwich and the county of Norfolk to give a study population representative of urban and rural practice which reflected the general population. Each general practitioner was asked to recruit only four patients. The Norwich district ethics committee approved the protocol for the study.

Patients were recruited by 31 general practitioners during a routine review of their epilepsy between 1 September 1996 and 31 March 1997. Consecutive patients over 16 years of age with a diagnosis of epilepsy were invited to take part in the study. Any patient who had had epilepsy diagnosed by a neurologist could be included, whether they were receiving antiepileptic drugs or not. Only patients who were personally responsible for the care of their epilepsy were included. Patients were informed, by their general practitioner and the patient information sheet, that the study was investigating control of seizures. Informed consent was obtained by the recruiting general practitioner. The seizure rate in the participants was analysed by directly comparing the dates of seizures given in both questionnaires.

Statistical methods

The data were coded as outlined above and analysed by Minitab 11 for Windows 95. We analysed the data

using parametric and non-parametric tests, as appropriate. Statistical tests for paired data, independent data, the comparison of proportions, analysis of variance, and logistic regression were used.

Results

A total of 122 patients was recruited by the general practitioners. The reported response rate was over 90%. Of these 122 patients, 111 (94%) returned the second, confidential questionnaire. These comprised 52 (48%) men and 59 (52%) women with a mean (SD) age of 48.5 (16) years (range 16-81 years) and a mean duration of illness of 21.5 (15.5) years. Sixty two (51%) subjects were in socioeconomic groups 4 and 5. The age and sex of the 111 respondents mirrored that found in previous studies of epilepsy in general practice (analysis of variance $W=68$, $P=0.87$).^{14 15} Analysis of the ages, sex, and type of epilepsy or frequency of seizures for the 11 non-respondents showed no significant differences from respondents (Mann-Whitney test $w=330.5$, $P=0.94$). In particular, five patients reported a seizure during the past 12 months and six did not.

Of the 111 respondents who completed the anonymous questionnaire, 42 admitted to their general practitioner that they had experienced a seizure during the past 12 months and 60 reported a seizure on the anonymous questionnaire (table 1). One patient reported a seizure to the general practitioner but not anonymously. No patients experienced seizures during the interval between completing the questionnaires. This difference was significant ($P<0.001$) and comparison of proportions indicated a 16% (95% confidence interval 9% to 23%) difference in the number of reported seizures.

Table 2 gives data on possession of driving licence and employment status according to reporting of seizures to general practitioners and anonymously. Six patients (out of 42) who reported a seizure to their general practitioner also reported having a driving licence, but 24 out of 60 patients with anonymously reported uncontrolled epilepsy possessed a licence (table 2). This difference was significant ($P<0.001$). Although patients were asked if they possessed a driving licence, they were not asked if they were currently driving. Therefore, we cannot assume that all patients with a licence were driving. However, several patients volunteered information in their questionnaire that

Table 2 Data on driving, employment, and mental health reported in questionnaires administered by general practitioners and self completed anonymously according to reporting of seizures in past year

	Seizures in past year		No seizures in past year		χ^2 (P value)
	General practitioner (n=42)	Anonymous (n=60)	General practitioner (n=69)	Anonymous (n=51)	
No with driving licence	6	24	16	26	17.3 (<0.001)*
No unemployed	14	16	9	7	9.38 (<0.01)
No retired	12	18	22	16	—
No of patients with scores >8 for:					
Depression	—	19	—	5	7.57 (0.006)
Anxiety	—	34	—	19	8.32 (0.004)
Stigma	—	33	—	9	17.53 (<0.0001)

*Comparison of proportions=0.237 (95% confidence interval 0.231 to 0.243).

indicated whether they were driving and the figures were adjusted accordingly.

After patients who had retired (including those retired on medical grounds) had been allowed for, the self reported unemployment rate for the study population was 32% (27 patients) of the economically active population (85 patients). Patients who had uncontrolled and unconcealed seizures (42) had an unemployment rate of 47% whereas patients with uncontrolled but concealed seizures (18) had an unemployment rate of 17% (difference in proportions 30% (95% confidence interval 27% to 33%), $P < 0.001$). At the time of the study the national unemployment rate was 9%.

Anxiety, depression, and stigma

Scores on the hospital anxiety and depression questionnaire showed a clear relation between current level of seizure activity and the patients' psychological wellbeing (table 2). The numbers of patients with scores > 8 for anxiety, depression, and stigma were significantly higher among patients with uncontrolled epilepsy (whether concealed or not) than among those with controlled epilepsy. Analysis of variance of the anxiety, depression, and stigma score with seizure during the past year produced *F* values of 17.22, 14.64, and 15.42 respectively ($P < 0.0001$ for all values). Respondents who had concealed their seizures had a lower mean stigma score than those who had not, although the difference was not significant.

Discussion

We found that reporting of seizures to general practitioners was significantly lower than reporting in an anonymous questionnaire. About a sixth of patients concealed seizures from their general practitioner. The anonymous reporting equates to an annual seizure rate of 53%. This is higher than the generally reported annual seizure rate of about 30%,¹⁶ although similar rates have been reported in other studies.^{14 17}

Scambler found that secrecy and concealment was epileptic patients' first choice strategy for managing their seizures.¹⁸ He developed the hidden distress model as an explanation for this strategy and introduced the concepts of felt and enacted stigma. Enacted stigma refers to episodes of discrimination against people with epilepsy on the grounds of social and cultural unacceptability. Felt stigma has two referents: the shame of having epilepsy and the fear of encountering enacted stigma.

Motives for concealment

Our results suggest that at least part of the motivation for concealing seizures was associated with three factors: current employment, possession of a driving licence, and the psychological correlates of epilepsy. We found that high scores for anxiety, depression, and stigmatisation were positively related to uncontrolled epilepsy. However, seizures are not the exclusive reason for the presence of psychological distress. Unemployment and the curtailment of driving privileges have psychological consequences in their own right. We could not investigate this further because of the small number of subjects and absence of a control population.

Key messages

- People with epilepsy may be reluctant to report seizures to their general practitioners as epilepsy affects their eligibility for a driving licence and access to various employment and leisure activities
- In this study about a sixth of patients anonymously reported seizures in the past year which they had not revealed to their general practitioner
- 40% of patients who anonymously reported a seizure in the past year held a driving licence, but only a quarter of these admitted this to their general practitioner
- People who had had seizures in the past year were significantly more depressed and felt more stigmatised than those who had not had a seizure
- Underreporting of seizures has important consequences for treatment, and doctors need to put more effort into explaining this to patients

Collings reported that unemployment was strongly predictive of depression and commented that people with epilepsy are overrepresented in unemployment statistics.¹⁷ We found that the unemployment rate in patients who had concealed their seizures was significantly lower (17%) than that in patients who had not concealed their seizures during the past year (47%).

The practical consequences of not being able or allowed to hold a driving licence are clear. However, there are also psychological consequences: 64% of patients with epilepsy expressed concerns about driving when questioned about quality of life issues.¹⁹ Scambler found that not being able to drive was stigmatising in its own right.¹⁸ Current UK legislation requires a person to be free of seizures for one year. This is based on research that suggests an increased accident rate among people with epilepsy. However, little evidence exists that certain types of epilepsy are predictive of an increased accident rate.^{7 20 21} Moreover, the more restrictive the law the more it is disobeyed,²² and as a consequence the more seizures concealed. If the findings of this study were reflected throughout the United Kingdom, there would be at least 24 000 people with uncontrolled epilepsy who hold a driving licence.

Consequences of concealment

The consequences of concealment of seizures from general practitioners include potentially inadequate treatment, barriers to doctor-patient communication, and failure to resolve the main referents of stigmatisation. From the patient's perspective, such problems are presumably outweighed by the benefits of concealment (being able to hold a driving licence, access to employment, minimisation of stigmatisation, etc). However, the extent to which patients accurately assess these costs and benefits is unclear.

Although the fact that some people conceal their seizures may not surprise doctors, it has potentially

important repercussions for treatment. Doctors may need to put more effort into explaining the potential consequences of concealment to the patient.

At a broader policy and legislative level, this study suggests that the government might need to consider reducing the period that epileptic patients are required to remain seizure free in order to hold a driving licence. For example, in Wisconsin, United States, which has one of the lowest accident rates measured,^{23 24} the current restriction on driving is three months.

This study was originally carried out for a dissertation for an MSc in health sciences at the University of East Anglia (School of Health Policy and Practice) by JD. We thank the general practitioners and patients who took part in the study and Miranda Mugford and Malcolm Adams for useful comments and statistical advice.

Contributors: JD designed and executed the study, did the analysis, and wrote the paper. JA gave technical help with study design, analysis, and writing the paper. JD is the guarantor.

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A faded memory My old school

A recent visit to my old school transported me back to 1961 when in the second week of February I arrived in London to join the London School of Hygiene and Tropical Medicine as a diploma student. My first meeting was with Professor Bertram of the division of medical entomology. He was instrumental in getting me an Andrew-Balfour memorial scholarship that paid for my tuition and made it possible for me to come to England.

Never before had I met a scientist of Professor Bertram's stature. He was kind and avuncular and inquired about my voyage, my boarding arrangements, and if I liked British food. After the interview he rose from his chair, escorted me across the room to the door, opened it, and wished me luck. He pointed out that there would be students from all over the world and that I would feel at home in London.

To this day I remember those words that had conjured such a positive image of physician scientists. We were taught tropical medicine by the giants in the field. The first lecture was given by Professor P C C Garnham, a towering figure in the field of malariology, who had discovered the exoerythrocytic cycle of *Plasmodium vivax* and showed that the organism was capable of surviving in the human liver for a long time.

Professor A W Woodruff was lean, lanky, serious, and Sherlockian in appearance, and thoughtful and masterly in discourse. I was lucky to have known him as he had visited India and knew many of my professors. Dr Robert Greenhill Cochrane had helped to set up the Union Medical College in Peking and the Leprosy Study Centre in Wimpole Street. A devout Christian with a sense of humour, he admonished, "There are no lepers; there are only patients with leprosy." The statement summarised his vision and dedication to the cause of leprosy.

Philip Manson-Barr taught about malaria. Sir Bradford Hill introduced statistics by alluding to Disraeli's words, "Lies, damn lies, and statistics." The ebullient and animated Professor

McDonald guided us through the mathematical maze of the epidemiology of malaria; the epidemic curves, the density and longevity of anopheline, important at that time, but now a faded memory.

Just a few blocks away at 136 Gower Street stood H K Lewis & Co Ltd, booksellers. Founded by Henry King Lewis in 1844, it was also a lending library. The membership dues were minimal. Members could borrow books, regardless of price. It was the best bargain for those of us who had come from overseas with limited funds. Neither the book dealership nor the library now exists. The premises are now part of University College Hospital.

The Wellcome Building, designed by Septimus Warwick and built by Sir Henry Wellcome, once contained the most comprehensive museum and library of tropical diseases. We would spend afternoons reviewing pathological specimens, chest x ray films, and beautifully drawn diagrams. The tropical disease museum, moved to another location, is no longer within easy reach for students at the school of hygiene.

The London School of Hygiene and Tropical Medicine continues to flourish. In increasing numbers students come from all corners of the world. But the image of my alma mater that existed in my memory no longer survives.

Om P Sharma *professor of medicine, Los Angeles*

We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.