Epilepsy: a general practice study of knowledge and attitudes among sufferers and non-sufferers

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SUMMARY. The aim of this study was to examine epilepsy sufferers' attitudes to and knowledge of their condition, the effect of epilepsy on their lives and their views on the management they had received, and to compare knowledge and attitudes with those of a control group of non-sufferers. A questionnaire was completed by 29 patients with epilepsy and 32 control group subjects from two general practices. It was found that people with epilepsy knew little more than those without epilepsy regarding the nature of the condition, its aetiology and seizure precipitants. Those with epilepsy were concerned about the seizures and the effect these had on various aspects of their lives, and were concerned about long-term side effects of anti-epileptic medication. There were no significant differences between the two groups with respect to educational achievement, employment record and social activities.

The findings are discussed and suggestions put forward for improving the care offered to epilepsy sufferers by both general practitioners and hospital clinics.

Keywords: epilepsy; patient attitude; patient knowledge; patient concerns; lifestyle.

Introduction

PILEPSY is a common medical problem carrying a considerable social stigms, which are able social stigma, which affects 2% of the population at some time in their lives. 1 Most people with epilepsy are managed in the community, without regular specialist review.² Hospital based clinics are biased towards people with chronic, drug resistant epilepsy, often in association with mental or physical handicap. Patients attending hospital clinics, especially neurology clinics, are atypical of people with epilepsy, 70% of epilepsy sufferers becoming free of seizures with therapy.3 A working group has proposed the setting up of epilepsy clinics, similar to the already established diabetes clinics,4 but little has been done to implement its proposals.

There have been many advances in the management of epilepsy in the last decade and a growing awareness of the sociological implications of the condition. Research has tried to evaluate models proposed to explain the social stigma of epilepsy⁵⁻⁷ and other studies have looked at the attitudes of doctors, teachers and parents towards adults and children with epilepsy.8-12

Little consideration has been given to what patients with epilepsy know and feel about their disorder. Research in Australia, 8,13,14 Nigeria 15 and the United States of America 6 has

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looked at the psychosocial consequence of epilepsy in samples of patients attending neurology clinics or belonging to an epilepsy association. Only one of these studies looked at a group of patients taken from a general practice sample. 13 From the studies it was found that many of the patients knew little about epilepsy, its nature, causes or medical management. Some had experienced major problems in social adjustment and stability, personal relationships and employment.^{6,13} Most felt their lifestyle was restricted because of their epilepsy and that they were stigmatized by their disorder.6,15

A community study was undertaken to explore epilepsy sufferers' attitudes to and knowledge of their condition, their views on how their epilepsy had been managed and suggestions for improvement, and how epilepsy affected their lives. Their knowledge and attitudes were compared with those of a control group of subjects without epilepsy so that the views of both groups could be considered in the establishment of a local epilepsy clinic.

Method

In 1989, all patients with epilepsy registered at two adjacent general practices in south west London and Surrey were identified by means of a general practice diagnostic index. All patients on anti-epileptic therapy were also identified from the practices' computers; their medical records were reviewed and those on drugs for conditions other than epilepsy were excluded. Full details of the type, duration and management of their epilepsy were not obtained as this information was not always available from general practitioner records. Those aged 16 years or over with no mental or physical handicap were included in the study. Letters were sent explaining the objectives of the study, together with a questionnaire to complete and return. Questionnaires were given to a control group of subjects, matched for age and sex, attending their general practitioners with self-limiting and minor problems. The questionnaire was handed to the patient by the doctor at the end of the consultation. Non-respondents in both groups were sent a letter and then followed up with a telephone

The questionnaire for epileptic patients covered eight main areas: patient knowledge and attitudes towards epilepsy, views on treatment, clinics attended, information provided, home circumstances, and effects of epilepsy on social life, employment and driving. The questions were a mixture of pre-coded and open questions. Space was provided for general comments and suggestions for improvements in care. A similar questionnaire was used in the anti-epileptic drug withdrawal study¹⁶ and has been described by Jacoby. 17 Control patients were given a similar but shorter questionnaire, and the results were compared using confidence interval analysis. 18,19

Results

Questionnaires were returned by 32 of the 51 epileptic patients (63%) and 32 of the 35 control subjects (91%). Three of the questionnaires returned by the epileptic patients contained hardly any replies to the questions so were excluded. Ten of the epileptic patients and 15 of the control subjects were men. The mean age of the 29 patients with epilepsy was 47.6 years (standard deviation (SD) 18.6 years) and for controls 48.5 years (SD 17.0 years), 95% confidence interval (CI) of the difference between proportions -0.1 to 0.8. There was no significant difference in social class distribution between the two groups.

Eighteen of the 29 epileptic patients (62%) knew the name of their form of epilepsy: six had grand mal, eight had petit mal, two had nocturnal epilepsy and two had temporal lobe epilepsy. Twelve (41%) knew the cause of their epilepsy: five had post-traumatic epilepsy, two had it as a result of a birth injury or congenital malformation, four from genetic causes and one thought the epilepsy was a result of cerebral disease. Eight patients (28%) had a positive family history of epilepsy (any relative affected), five had a first degree relative affected and three had a second degree relative affected.

Of the 32 controls 72% knew or had met someone with epilepsy; seven of the 32 had a relative with epilepsy. Eighteen had witnessed a seizure, usually a grand mal fit.

General knowledge about epilepsy

The two groups' general knowledge about epilepsy was assessed (Table 1). Those with epilepsy were more likely to know that there were different kinds of epilepsy and to be able to name petit mal and grand mal forms. However, few patients in either group could name other forms of epilepsy. Regarding its aeti-

Table 1. Knowledge of epilepsy among those with and without the condition.

Knowledge of epilepsy	% of patients		
	With epilepsy (n = 29)	Without epilepsy (n = 32)	95% confidence interval of difference
Knows there are different			
kinds	86	47	18.0 to 60.7 *
Can name types			
Grand mal	62	22	17.5 to 62.9 *
Petit mal	66	22	21.2 to 66.1 *
Temporal lobe	10	- <u>-</u>	-0.7 to 21.4
Other, eg, Jacksonian	38	34	-20.6 to 27.7
Can name causes			
Cerebral disease	24	13	-7.7 to 31.0
Genetic	21	3	1.6 to 33.5 *
Birth injury/congenital			
malformation	17	3	-0.9 to 29.1
Metabolic disorders	7	6	-11.8 to 13.1
Post-infective	7	3	-7.3 to 14.8
Severe febrile convulsion	3	3	<i>–8.6</i> to <i>9.3</i>
Drugs/toxins	0	0	
Post-traumatic	0	16	<i>–28.2</i> to <i>–3.0</i> *
Unknown aetiology	0	0	
Knows there are			
precipitants of seizures	59	41	-6.7 to 42.7
Can name precipitants			
Interpersonal stress/tension		25	6.6 to 53.7 *
Emotional disturbanceb	34	<i>38</i>	-27.1 to 21.1
Photic cause	34	9	<i>–6.2</i> to <i>37.7</i>
Sleep deprivation/fatigue	21	<i>3</i>	1.6 to 33.5 *
Impaired physical health	7	0	-2.3 to 16.1
Starvation/hypoglycaemia Non-compliance with	a 7	0	–2.0 to 16.1
medication	3	6	-13.5 to 7.9
Premenstrual condition	Õ	ŏ	
Psychogenic cause	Õ	Õ	
Transient hypoxia	Õ	Õ	
Other, eg, excess alcohol	3	6	-13.5 to 7.9

n = number of patients in group. a Classified according to Lishmann. 20 b Including shock, surprise, stress, excitement. * P<0.05.

ology, more patients with epilepsy could name a cause compared with controls. Significantly more patients with epilepsy cited genetic factors as a cause than controls while significantly more control subjects cited trauma as a cause than epilepsy sufferers. Regarding precipitants of seizure, significantly more epilepsy sufferers cited sleep deprivation and fatigue than controls and interpersonal stress and tension.

When the control group were asked what they would do if they witnessed a seizure the responses were: protect the person from injury (50%), make the person comfortable/loosen clothes/try to help (50%), turn the person on his/her side (34%), make sure the person did not swallow his/her tongue (28%), put an object in the person's mouth to prevent the tongue being bitten (22%), call for medical help/for an ambulance (16%), leave alone or wait (9%).

Only seven patients with epilepsy felt they knew as much as they would like to about the condition. Thirteen had heard of the British Epilepsy Association but only two were members. Eleven (38%) had seen or read a book or leaflet about epilepsy.

Attitudes to epilepsy

People with epilepsy were more likely than the controls to regard it as a minor illness. For example, those with epilepsy who gave a response said their own fits were well controlled (nine patients) and did not interfere with their lives (six), the seizures were mild or not noticeable to others (six) and posed no danger (one). The control subjects were more likely to regard epilepsy as a severe illness: it could be life threatening or dangerous to the patient (four subjects), it interfered with normal life (three), there was no cure (two), there had been adverse publicity (one) and it occurred without warning, needing immediate treatment (two) (not all control subjects gave a response). One subject knew someone who had died during an epileptic fit.

Eighteen of the control group (62%) said they would let their children marry someone with epilepsy and 38% did not know, no one said 'no'.

Those with epilepsy were asked how concerned the person they lived with was about their condition. Of the 17 patients living with a partner, 88% rated the partners as showing a little, some or a lot of concern; only 12% rated the partners as expressing no concern. Both the patients living with their parents thought their parents showed some or a lot of concern. Twelve patients had children – eight children knew of their parents' epilepsy and half of these children were greatly concerned, three showed a little or some concern and one showed no concern.

Ten sufferers had told all their friends about their epilepsy, 15 had told some of their friends, while four had not told any of their friends. While 24 sufferers (83%) felt that having epilepsy made no difference to their abilities to form friendships, 17% thought it made it more difficult. A minority thought other people were uncomfortable with them (24%), treated them as inferior (14%) or avoided them (14%).

Concerns of epilepsy sufferers

Ten per cent of sufferers were very concerned about their epilepsy, 72% were a little concerned and 17% were not concerned at all. The reasons for their concern are shown in Table 2 and the main areas were the unpredictability of seizures and possible teratogenic effects.

Twenty one per cent of patients were moderately concerned about their anti-epileptic medication and 55% were a little concerned (seven said they were not concerned). Specific concerns about medication were expressed by 66% and the main worries were related to side effects and the risk of drug dependence (Table 2).

When asked to state what was the most distressing aspect of having epilepsy, 35% stated the seizures themselves and the

Table 2. Epilepsy sufferers' main concern about their condition and medication.

	% of respondents (n = 29)
Main concern about condition ^a	
Unpredictability of fits	17
Effects on pregnancy/childbearing	13
Others' reactions	10
Having a fit when alone	10
Having to take medication	10
Having a fit when out	10
Restrictions on life	7
Fits themselves	7
Not being 100% fit	7
Effects on employment	7 7 3 3 3
Lack of control during fit	3
Possibility of condition worsening	3
Main concern about medication	
Side effects	24
Dependence	10
Maintaining correct level of medication in bloo	
Effects of missed doses	3
Weight gain	3 3 3 3 3
Effects on pregnancy/childbearing	3
Obtaining medication from doctor/chemist	. 3
Taking medication when away from home	3
Effect on liver	3

n = number of patients with epilepsy. *One patient listed two concerns.

associated memory loss and embarrassment, 14% stated the loss of control or unpredictability, 17% the distress of having a seizure when out or in front of strangers, 7% having to be on long-term medication, and 7% having no driving licence (two patients gave two responses and 27% gave other reasons).

Social life, employment and driving

There were no differences between the two groups in terms of the proportions who were married or cohabiting, had children, or lived with parents, others or alone. Both groups were asked how many times in the last three months they had been involved in a wide variety of social activities; no significant differences were found between the two groups. However, 17 respondents with epilepsy (59%) said that they did things less often because of their condition whereas 22% of the 32 controls felt their social activities were limited by health problems (most commonly, arthritis). Examples of reasons given by epilepsy sufferers included being unable to drive and having seizures brought on by flashing lights.

There were no significant differences between the two groups in terms of level of education and employment. However, 29% of those with epilepsy felt that the condition made it more difficult for them to get a job. Only 49% had told their employers about their epilepsy. The reactions encountered at work included concern about what to do if a seizure occurred at work, being treated differently, being transferred and referral to the company doctor and/or a neurologist. Two patients had, at some time, been advised by a doctor not to disclose their epilepsy to their employer. Overall, it was felt that fear, ignorance and prejudice occurred and declaration of epilepsy on a job application form could lead to problems.

Of the people with epilepsy 16 (55%) thought they were eligible to hold driving licence but only 10 had a current licence. Of the remaining 19, eight cited their seizure disorder as the reason while 11 gave other reasons for not driving.

Treatment

Seventeen epilepsy sufferers (59%) were attending their general practitioner for their condition, 14 (48%) attended a neurology outpatient clinic and three attended a hospital epilepsy clinic; one was not seeing a doctor at all (some patients were attending both a general practitioner and a hospital clinic).

Views on care received by patients at the general practice and the hospital neurology clinic are shown in Table 3. For most aspects the general practice and hospital clinics were rated comparably. However, 36% of patients attending a hospital clinic felt that they did not spend enough time with the doctor compared with only 6% of those seen in general practice. There was a nonsignificant trend towards patients being more likely to understand all of what a general practitioner rather than a hospital doctor said (Mann Whitney U test). Of the 14 attending hospital neurology clinics 36% saw different junior doctors most of the time. This was not felt to be satisfactory because they were regarded as taking too long, not being familiar with an individual's background history and making contradictory statements. Four patients were critical of the length of time it took to get a hospital appointment. There was only one criticism of general practitioner care, where a patient said male patients should see a male doctor.

Eighteen (62%) had been able to discuss with a doctor the effect of epilepsy on their work or social activities, 66% had discussed alcohol and driving and 52% had discussed childbearing.

Table 3. Views of patients receiving care in general practice and at the hospital neurology clinics.

	% of par	tients at ^a	95% confidence interval of difference
	General practice (n = 17)	Hospital (n = 14)	
Find consultation			
Helpful	53	64	-45.9 to 23.2
Not very helpful	6	21	<i>–39.8</i> to <i>6.7</i>
Waste of time	0	14	-32.6 to 4.0
Non-response	41	0	
Amount of time spent waiting			
Too much	12	<i>36</i>	<i>-53.4</i> to <i>5.5</i>
Acceptable	24	43	-52.2 to 13.5
Not much	<i>3</i> 5	21	-17.4 to 45.1
Non-response	29	0	
Time spent with doctor			
Enough	47	50	-38.3 to 32.4
Almost enough	6	7	-18.8 to 16.3
Not enough	6	<i>36</i>	-57.3 to -2.4*
Non-response	41	7	
Understand what doctors	S		
AlÍ	41	29	_
Most	12	50	_
Some	6	7	-
Hardly any	0	7	-
None	0	0	-
Non-response	41	7	-
Find explanation			
Helpful	<i>53</i>	71	-52.0 to 15.0
Not very helpful	6	21	<i>–39.8</i> to <i>6.7</i>
Non-response	41	7	
Can ask anything	<i>65</i>	<i>86</i>	<i>–50.2</i> to <i>8.2</i>
Non-response	<i>35</i>	14	

n = number of patients in group. *Patients attending both the hospital and the general practice answered questions on both. *P < 0.05.mm

Patients' suggestions for improvement

Patients were asked to make any number of suggestions for improvements in care. These related to three main areas. The first was the doctor-patient relationship: 11 felt it important to be seen by the same doctor (either in hospital or in general practice) who understood them, gave them a chance to express their feelings and gave them sufficient time. The second area concerned provision of information: four felt they needed more information about epilepsy, its nature, management and anti-epileptic therapy. Doctors should be able to provide more verbal and written information (six patients). The third area concerned meeting others with epilepsy and thereby feeling less alone, and being able to share information, advice and support (expressed by four patients).

Discussion

Differences in response rates were probably because the control group were asked to complete the questionnaire in the surgery while those with epilepsy were sent theirs by post. As there is no information on the non-respondents, non-respondents could be a self selected group possibly with greater social problems.

It is worrying that people with epilepsy knew little more than the control group regarding the nature of epilepsy, its aetiology and seizure precipitants. This low level of knowledge is consistent with the findings of other studies^{17,21} where most sufferers were ignorant about the causes of epilepsy and wanted to know more. Others have shown that sufferers of epilepsy restrict their lifestyle because of fear, misconceptions or appropriate avoidance of precipitants. 6,14,22 Full compliance with medication is rare and this may be in part due to lack of knowledge regarding the importance of regular medicine. 23,24

The present sample of patients with epilepsy tended to regard the condition as a mild disorder not incompatible with a normal life which contrasts with other surveys of sufferers⁶ and general practitioners8 where epilepsy has been seen as life threatening and something to be continually dreaded or a condition resulting in psychological instability, employment difficulties and a poor quality of family life. The areas of concern to the patients studied here (for example, epilepsy itself, anti-epileptic therapy, and others' reactions) are similar to those of other samples studied^{10,25,26} but less extreme than those described by Mittan and colleagues.⁶ They found high levels of anxiety regarding the seizures themselves and the possible destructive consequences of epilepsy, associated with poor coping abilities.⁶ However, their sample was drawn from an epilepsy clinic where more severe cases are found. The national general practice study of epilepsy found that many people with epilepsy experienced some psychosocial effects but only a minority had severe problems.²⁶

Few patients reported having experienced marked negative attitudes to their epilepsy. Most felt it made little difference to relationships (although others were concerned) but they were more inclined to limit social activities on account of their epilepsy. However, there were no actual differences in terms of the amount or type of social activities engaged in. Again, this contrasts with other research which has shown global social withdrawal⁶ or marked socioeconomic accompaniments in severe epilepsy.²⁷

There was no difference in the proportion of those married between those with and without epilepsy. There were also no differences between the two groups in terms of education and employment. This contrasts with a community based survey in the north east of England which found that people with epilepsy were less likely to leave school with qualifications, have subsequent training or apprenticeships and were more likely to be unemployed or be in unskilled manual occupations than those without epilepsy.¹² Other surveys in the United Kingdom have reported varying employment rates of 60-91% 17,28,29 or rates no different from those of the general population.⁷

The fact that people with epilepsy felt the condition made it more difficult to obtain employment and restricted their social lives when no statistical differences were found between sufferers and non-sufferers lends support to the hypothesis that the stigma associated with epilepsy is a result of the individual's perception and fears of stigma (perceived stigma) rather than enacted stigma (that is, actual negative practices and attitudes encountered). Scrambler and Hopkins found no evidence to support the orthodox view that the public are ignorant of epilepsy, have negative attitudes towards sufferers, are prone to discriminate against them and are thereby responsible for most of the problems.⁷ Our results support this: the majority of the control group had met or knew someone with epilepsy, most were concerned to be able to help and would let their children marry someone with epilepsy.

While the importance of long-term management plans and support for the patient and family has been stressed in the management of any neurological illness³⁰ this is of particular importance in epilepsy which is a potentially lifelong disorder with profound implications for the affected person. After auditing the care of people with epilepsy in one general practice, Lloyd-Jones stressed that counselling and up to date advice were important aspects of care.21 Lloyd-Jones found a serious discrepancy between what doctors did and what patients needed.

Management should be aimed at preventing attacks, and dealing with possible effects on lifestyle, and this should involve the spouse or partner.³⁰ Discussion would aid understanding and thereby improve patient compliance and well being. Patients need more counselling, especially in the adjustment period after the diagnosis is first made, regular ongoing medical surveillance, and need to be informed of the British Epilepsy Association and its literature.²⁴ It is sad that many patients felt that doctors' explanations could have been fuller, more informative and personally relevant. The suggestions they made regarding possible improvements in the service have been incorporated into the general practices and hospital clinics concerned.

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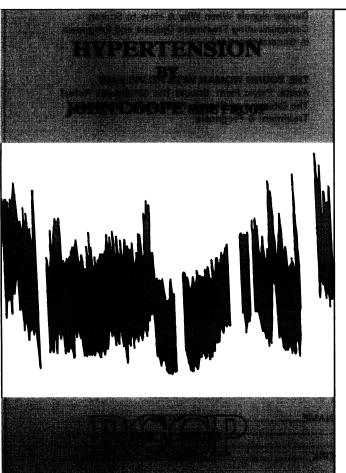
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