

Assessing the psychosocial consequences of epilepsy: a community-based study

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SUMMARY

Background. Few studies have measured, using validated scales, the psychosocial handicap of epilepsy in a general practice setting.

Aim. To assess the prevalence of psychosocial problems associated with epilepsy.

Method. A survey was undertaken of 309 subjects, with one or more non-febrile epileptic seizures, drawn from two general practices in the United Kingdom (UK). The outcome measures were the Subjective Handicap of Epilepsy Scale (SHE), the SF-36, and the Hospital Anxiety and Depression scale (HAD).

Results. One-third of persons with active epilepsy were significantly handicapped by their condition. The severity of subjective handicap was related to seizure frequency and to the duration of remission of seizures. Between one-third and one-half of subjects scored as 'cases' on the HAD scale and on the mental health subscale of the SF-36. Only one-third of the psychiatric morbidity revealed by the questionnaires had been recognized by the general practitioner (GP). Scores on the SF-36 indicated that people with active seizures perceived themselves as significantly less healthy than those in remission, and that, for persons in remission, drug treatment had a detrimental effect on certain aspects of well-being.

Conclusions. The occurrence of seizures, even at low frequencies, is associated with psychosocial handicap, and this may remain covert in general practice.

Keywords: epilepsy; handicap; health status; depression; anxiety.

Introduction

COMMUNITY surveys have indicated that people with epilepsy experience difficulties with work and social activities, particularly if they have frequent seizures.¹⁻⁶ People subjected to more than one seizure a month have two to three times the rate of psychiatric disorder compared with those in remission.^{4,7} However, the proportion of patients in a general practice setting who are significantly handicapped by their epilepsy remains

uncertain. Handicap is the disadvantage in living out a normal role in society an individual faces as a consequence of ill health.⁸ Subjective handicap is a person's own perspective on the degree of handicap. A scale to measure the Subjective Handicap of Epilepsy (SHE) has recently been developed and validated.⁹

This study was carried out to determine, in a community-based sample of people with active and remitted epilepsy, the impact of epilepsy on objective indices of handicap (e.g. unemployment), the subjective handicap of epilepsy, and levels of self-reported general and mental health compared with UK normative data.

Method

Identification of persons with epilepsy

The survey was conducted in two large group general practices in the UK, both having a long-standing interest in the treatment and audit of epilepsy.^{10,11} The disease and drug treatment registers were searched to identify persons having at least one non-febrile epileptic seizure (excluding seizures confined to the first year of life). This was supplemented by a manual search of all the medical records for mention of epilepsy in a subset of 6000 inhabitants of one practice. The records of identified cases were reviewed to determine seizure type, epilepsy syndrome, age at onset, date of most recent seizure, and current treatment status. Active epilepsy was defined as a seizure within the two years preceding 1 January 1996. 'On treatment' was defined as taking regular anti-epileptic drugs on 1 January 1996. Co-morbidity was defined as any major illness or disabling condition present within the past two years. Consultations recorded by the GP for depression, anxiety, psychosis, attempted self-harm, or other psychiatric symptoms were noted, as were the use of antidepressant or antipsychotic medication.

Survey methods

All persons with epilepsy or a single epileptic seizure, aged 15 years or over, were eligible for the survey, except for subjects with known severe learning disability or other severe physical disabilities that would preclude completion of the questionnaire. The survey booklet included the Subjective Handicap of Epilepsy Scale (SHE),⁹ the SF-36,¹² and the Hospital Anxiety and Depression scale.¹³ The SHE is a measure of the handicapping effect of epilepsy on daily life. The six subscales measure the effect on daily activity ('Work and Activity'), social life ('Social and Personal'), the physical effects of epilepsy ('Physical'), worry and self-confidence ('Self-Perception'), happiness with life ('Life Satisfaction'), and change over the past year ('Change'). All the subscales are scored from 0 to 100: 0 representing the most severe handicap. The SF-36 scales cover physical health, role functioning (daily activity), pain, energy, social functioning, mental health (the Mental Health Inventory - MHI-5), and health perception. All scales are scored from 0 to 100, with 100 representing optimum health. The questionnaire was mailed to subjects and one reminder letter was sent after six weeks.

Seizure data

Seizure frequency for responders was divided into more than one seizure per month; fewer than one seizure per month, but at least one in the past 12 months; and no seizures for 12-24 months,

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2–5 years, 5–10 years, 10–20 years, and more than 20 years. For non-responders, seizures were classified (from GP notes) into: at least one seizure in the past two years; no seizure in the past two years, but on anti-epileptic drug (AED) therapy; and no seizures in the past two years and no AED therapy.

Identification of psychiatric caseness and subjective handicap

The Hospital Anxiety and Depression scale (HAD) was used as a measure of anxiety and depression, with cut-off scores of 10/11 for a definite, and 7/8 for a borderline case, as in previous studies.^{4,7,14} The Mental Health Inventory (MHI-5) consists of five items scored on a 6-point Likert scale.¹² Responders scoring on all the lowest three points of each scale item (resulting in a MHI-5 of less than 40) have a 70–80% chance of scoring above the cut-off for depression on the Centre for Epidemiological Studies Depression scale,¹⁵ or a 30–50% chance of a DSM-III diagnosis of major depression.¹² For subjective handicap, no criterion exists for 'severe handicap'. As a cut-off point, we used the median SHE score of 157 patients being considered for epilepsy surgery.⁹ This was chosen on the assumption that patients who desired epilepsy surgery were severely handicapped by their condition.

Analysis

The clinical characteristics of responders and non-responders were compared. A planned comparison of mean SHE and SF-36 scores of all persons with active epilepsy versus cases in remission was carried out. The scores on the SHE were compared for persons with differing seizure frequencies and lengths of remission. The impact of anti-epileptic drug treatment on SHE and SF-36 scores was assessed by a comparison of patients in remission on and off treatment. The UK norms for the SF-36 are included for comparison with the epilepsy sample.¹⁶ All comparisons were performed with non-parametric statistics.

Results

Clinical characteristics

Three hundred and sixty-nine persons with epilepsy, active or remitted, were identified. Forty-four per cent were male and the median age was 44 years. The prevalence of active epilepsy in the combined population was 3.7 per 1000. For those on anti-epileptic drug treatment, whether active or remitted, the prevalence was 7 per 1000. Forty-one subjects were not sent a questionnaire because they were under 15 years old, and 19 because of severe physical and learning disabilities. An overall response rate of 57% was obtained, which rose to 70% in those with active epilepsy. Responders were significantly more likely to be female, to have active epilepsy, and to have had epilepsy for a longer duration (Table 1). Among the responders, 69 had active epilepsy, 53 had epilepsy in remission on AED treatment, and 53 were remitted off therapy. Twenty-eight (16.5%) persons had more than one seizure per month, 26 (15.3%) had less than one seizure per month but more than one per year, 15 (8.8%) had their last seizure 12–24 months ago, 22 (12.9%) were in a 2–5 year remission, 19 (11.2%) in a 5–10 year remission, 37 (21.8%) in a 10–20 year remission, 23 (13.5%) in greater than a 20 year remission, and in five the date was unknown.

Objective handicap

Of responders of working age with active epilepsy, 34% were unemployed or off work owing to disability, compared with 11% of those whose epilepsy was in remission. One-third thought they had been turned down for a job because of their epilepsy and one-quarter felt that they had been dismissed from a job because

of it. Social security benefits were the main source of income for 40% of those with active epilepsy, compared with 12% of those with remitted epilepsy.

Subjective Handicap and General Health

The Subjective Handicap of Epilepsy scores revealed decreasing handicap (or better 'functioning') as seizure frequency decreased and the length of remission increased (Table 2). Beyond 5–10 years, the scores reached a plateau. A comparison of active versus remitted epilepsy was significant for all scales except 'Change' (Mann–Whitney: $P < 0.0001$). A comparison between more than and less than one seizure per month was significant for four of the scales (Table 2). The mean score on the 'Change' scale did not vary between groups, suggesting that the SHE measured a stable trait. There was a significant difference on scores on the 'Life-Satisfaction' (Mann–Whitney: $P < 0.007$) and 'Physical' (Mann–Whitney: $P < 0.03$) scales when comparing remitted persons on and off AED treatment. One-third of all cases of active epilepsy were found to be subjectively handicapped on the four SHE scales (Table 3); the proportion rising to one half if seizures occurred more than monthly. In the 6000 inhabitants in which the ascertainment of epilepsy (active or in remission) was complete, about 10% were classified as handicapped because of epilepsy. Scores on the SF-36 scale for persons in remission were higher than for those with active epilepsy (indicating better health) for all eight scales (Table 4). Scores on the 'Vitality' and 'General Health' scales indicated better health in those who had discontinued anti-epileptic drugs compared with those on treatment but in remission (Table 4).

The prevalence of psychiatric symptoms

One hundred and twenty-four (34%) subjects had consulted their GP at some point for psychiatric symptoms, and 64 (17%) had done so in the previous two years: depression (23%), anxiety (6.5%), and overdose (6%) were the commonest reasons. Thirty-three patients (9%) were taking antidepressant medication. The prevalence of recorded psychiatric symptoms in the past two years in those with active epilepsy was 20%; in those with remitted epilepsy on AED treatment, 18%; and remitted off treatment, 17%. About one-half of persons having more than one seizure per month, and one-fifth of those in remission, were classified as having definite depression or anxiety on the HAD (Table 5). Thirty per cent of those with more than one seizure per month were 'cases' on the MHI-5, compared with 23% of those with less than one seizure per month, 14% of those with epilepsy in remission on AED treatment, and 4% with remitted epilepsy off AED treatment. Only one-third of those who were classified as a definite or borderline 'case' on the HAD had a record of psychological symptoms in their medical notes in the past two years.

Discussion

Scores on the SHE and SF-36 scales showed a clear relationship with the severity of epilepsy. The largest difference was between active and remitted epilepsy. The higher scores that occurred with longer remission probably reflected increasing confidence that epilepsy had finally 'resolved'. The SHE 'Life-Satisfaction' and 'Physical' scales, and the SF-36 'Vitality' and 'General Health' scales showed a beneficial effect of not being on AED treatment for those in remission.

The subjective handicap associated with epilepsy appeared to be under-recognized. Half of the subjects with more than one seizure per month were as severely handicapped as patients drawn from an epilepsy surgery programme. Given the degree of self-perceived handicap, the proportion of patients that were

Table 1. Clinical characteristics of responders and non-responders.

	Responders	Non-responders
Male n (%)	65 (49)	69 (51) ^a
Female n (%)	110 (63)	65 (37)
Age (median years)	45.5	43.5
Age at onset of epilepsy (median years)	21	18.5
Duration of epilepsy (median years)	11	6 ^b
Comorbidity present (%)	43	40
History of psychiatric consultation in past 2 years (%)	17	18
Response rate according to seizures n (%)		
Active epilepsy	69 (70)	29 (30) ^c
Remitted on treatment	53 (47)	59 (53)
Remitted off treatment	53 (54)	46 (46)

^aMore female responders ($c^2 = 6.4$; $P = 0.011$); ^bshorter duration of epilepsy in non-responders ($P < 0.01$); ^cmore responders with active epilepsy ($c^2 = 11.9$, $P = 0.003$).

Table 2. Median (interquartile range) SHE scores according to seizure frequency or years in remission.

Seizure category	Work and activity	Social	Physical	Self-perception	Life-satisfaction	Change
> 1 seizure per month	44 (28–69) ^{a,b}	72 (44–88) ^a	38 (19–62) ^{a,c}	33 (20–68) ^{a,c}	53 (41–69) ^a	46 (36, 52) ^c
< 1 seizure per month	69 (53–91) ^d	88 (62–100)	56 (38–75)	60 (45–90)	59 (44–75)	50 (50, 61)
1–2 years remission	100 (72–100)	88 (88–100)	69 (50–88)	75 (40–90)	75 (56–88)	57 (50, 64)
2–5 years remission	97 (86–100)	100 (94–100)	75 (62–85)	75 (65–90)	75 (50–81)	54 (50, 68)
5–10 years remission	100 (97–100)	100 (100–100)	81 (69–88)	90 (80–100)	75 (56–94)	52 (50, 64)
10–20 years remission	100 (100–100)	100 (100–100)	88 (75–94)	95 (85–100)	81 (69–94)	50 (50, 61)
> 20 years remission	100 (100–100)	100 (100–100)	88 (75–94)	100 (95–100)	88 (75–100)	50 (50, 50)

^aSignificant difference in SHE score for active versus remitted epilepsy ($P < 0.00001$); ^bsignificant difference in SHE score for > 1 per month versus < 1 per month ($P < 0.01$); ^c($P < 0.03$); ^dsignificant difference in SHE score for < 1 per month versus 1–2 year remission ($P < 0.003$).

Table 3. Percentage of subjects scoring as cases of 'subjective handicap' (95% CI) on four SHE scales according to seizure and treatment status.

SHE scale	Active epilepsy		Remitted epilepsy	
	All active epilepsy (n = 68)	More than one seizure per month (n = 28)	On AED treatment (n = 50)	Off AED treatment (n = 50)
Work and activity scale	32 (21–43)	56 (38–74)	0	0
Social scale	29 (19–39)	46 (28–64)	8	0
Physical scale	37 (26–48)	54 (36–72)	4	0
Self-perception scale	34 (23–45)	54 (36–72)	2	2

Note: Case of 'subjective handicap' defined by a SHE scale score below median score of 157 epilepsy surgery candidates.⁹ Base varies slightly due to subjects with missing responses. AED = anti-epileptic drug.

Table 4. Median, mean (interquartile range) SF-36 scale scores for three seizure activity categories compared with UK normative data.

Seizure Status (n)	SF-36 scale							
	Physical F	Role P	Role E	Vitality	General H	Pain	Social F	Mental H
Active epilepsy (65)	90,73 (58–100) ^c	75,58 (0–100) ^a	67,59 (0–100) ^a	40,48 (30–70) ^b	62,61 (40–82) ^c	78,70 (44–100) ^c	78,70 (44–100) ^b	64,61 (40–80) ^b
Remission on AEDs (50)	95,83 (80–100)	100,80 (75–100)	100,85 (100–100)	55,55 (35–75)	67,66 (52–77)	89,80 (67–100)	100,85 (67–100)	74,69 (56–88)
Remission off AEDs (50)	100,92 (90–100)	100,88 (100–100)	100,88 (100–100)	65,67 (55–80) ^e	82,78 (67–95) ^d	100,86 (78–100)	100,92 (89–100)	80,75 (64–88)
UK norms 20–24 years (1008)	91.6	90.4	80.4	62.2	74.5	84.3	87.8	72.0
UK norms 60–64 years (525)	76.2	75.9	84.8	61.8	68.1	76.9	86.2	76.4

^aSignificant difference in SF-36 score for persons with active epilepsy versus all remitted epilepsy ($P < 0.0001$); ^b($P < 0.001$); ^c($P < 0.01$) (Mann-Whitney test); ^dsignificant difference in SF-36 score for all persons in remission on versus off AED treatment ($P < 0.003$); ^e($P < 0.01$) (Mann-Whitney test). Abbreviations: AEDs = anti-epileptic drugs; General H = general health; Mental H = mental health; Physical F = physical function; Role-E = role emotional; Role-P = role physical; Social F = social function.

Table 5. Percentage of subjects scoring as cases of 'anxiety and depression' on the HAD (95% CI) according to seizure and treatment status.

	Active epilepsy		Remitted epilepsy	
	More than one seizure per month (n = 27)	Less than one seizure per month (n = 36)	On AED treatment (n = 49)	Off AED treatment (n = 43)
Definite anxiety	48 (29–67)	33 (18–48)	20 (9–31)	19 (7–30)
Definite depression	33 (15–50)	11 (1–21)	6 (0–13)	0
Definite anxiety or depression	55 (36–74)	39 (20–54)	20 (9–31)	19 (7–30)

Base = 155 due to missing responses on 20 subjects.

receiving specialist treatment was not high. Only 16 (24%) of the active epilepsy patients surveyed were under on-going neurological follow-up.

The high prevalence of 'caseness' on the HAD is comparable to previous studies.^{4,7} The community prevalence of psychiatric disorder diagnosable by ICD-9 criteria is of the order of 10%,¹⁷ although this rises to 13–18% if screening questionnaires are employed.^{18,19} The prevalence of mood disorder in our sample of people with remitted epilepsy off treatment was comparable to the population average figure. Although the persons identified as psychiatric 'cases' were not subsequently assessed using research diagnostic criteria, the convergent evidence from the two mental health scales used suggests that a significant fraction had a mood disorder. These symptoms were often not recognized by, or had not presented to, the GP.

It is now appreciated that psychiatric illness may go unnoticed in general practice,²⁰ and that psychiatric illness detected using survey questionnaires are not necessarily less severe than those already known to the health services.²¹ Previous studies have suggested that concurrent physical illness is associated with a lack of recognition of depression by GPs.²⁰ In the case of epilepsy, it is possible that attention is focused, by the patient and the physician, on recurrent seizures, and that psychological aspects remain hidden or attributed to the seizures.

A number of methodological limitations apply to the study. First, the sample size is modest; secondly, the overall response rate of 57% is somewhat low, although the response rate for people with active epilepsy (70%) is comparable to similar studies. We also excluded those whom we knew would not be able to complete the questionnaire. It is likely that this group is particularly handicapped by epilepsy and associated neurological impairments, and further research on these subjects would be valuable. Finally, the general practices sampled may not be wholly representative of all practices, given their established interest in epilepsy management.

In conclusion, about one-third of people in the community with active epilepsy were found to be significantly handicapped by their condition: even occasional seizures being associated with subjective handicap and a greater than expected incidence of psychiatric symptoms. Whether interventions specifically directed at handicap are helpful for people for whom seizure freedom is currently not possible is unclear. Prospective longitudinal studies are underway to address this.

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