

# The effect of a special nurse on patients' knowledge of epilepsy and their emotional state

L RIDSDALE

I KWAN

C CRYER

THE EPILEPSY EVALUATION CARE GROUP

## SUMMARY

**Background.** People with epilepsy often report being given insufficient information and support. However, there is little evidence from general practice about how much they know and how they feel.

**Aim.** To describe social differences in the knowledge of epilepsy of people with the condition and test the potential effect of a nurse intervention in general practice on patients' knowledge and depression levels.

**Method.** A questionnaire that included measures of knowledge, anxiety, and depression was sent to people with epilepsy aged over 15 years who were registered with 37 general practitioners. Responders were randomized to a controlled trial, offering either two appointments with an epilepsy nurse or usual care. Six months later they were reassessed.

**Results.** Two hundred and fifty-one out of 283 (89%) of the patients with epilepsy completed questionnaires and entered the study at Stage 1. One hundred and ninety-six out of 232 (84%) of those who entered the study, who remained in the practices and were eligible, returned questionnaires at Stage 2. The average duration of epilepsy was 23 years (range 2–79 years). There were significant differences in patients' levels of knowledge of epilepsy at Stage 1. Younger people, those who had left school after 16 years of age, those with GCSEs, and people who belonged to self-help groups had higher knowledge levels, and these were independent effects. Older people and those with a recent epilepsy attack had significantly higher depression scores. Knowledge scores did not differ significantly after the nurse intervention (Stage 2). At Stage 2, the risk of depression was less in the group randomized to be offered nurse input; the effect was mainly in a subgroup of patients with no recent epilepsy attack; their risk of depression was a third of the risk in the control group.

**Conclusions.** Knowledge of epilepsy differs significantly, with social factors and self-help group membership having independent effects. A nurse-run clinic reduced the risk of depression for people with no recent epilepsy attack, but knowledge levels were not affected. This does not exclude the potential for patients learning more about epilepsy; it may

be useful to suggest that patients join self-help groups early on.

**Keywords:** epilepsy; nurse; primary health care; health education; psychology.

## Introduction

SELF-HELP groups<sup>1</sup> and social scientists<sup>2</sup> have commented that epilepsy sufferers report that they are provided with too little information and support for them to manage their condition as well as they would wish. In the context of an audit, we identified a group of people with epilepsy in primary care and described the advice that had been recorded as provided in the clinical notes,<sup>3</sup> the responders' psychological state, and their perception of stigma.<sup>4</sup> We found that, for many important aspects of epilepsy self-management, there was no record of advice having been given to over half of the patients.<sup>3</sup> One-third of the people with epilepsy reported experiencing attacks in the previous six months; these responders had three times the risk of a high depression score and the sense of being more stigmatized than people with no recent attack.<sup>4</sup> These findings are supported by studies in general practice in other parts of the country.<sup>5,6</sup>

It has been suggested that nurses with special training may be able to provide advice and support for patients with epilepsy, just as they already do in similar chronic conditions, such as diabetes.<sup>7</sup> We therefore tested the feasibility of setting up a nurse-run epilepsy clinic in primary care and its effect on information recorded as provided in the clinical records.<sup>8</sup> We also measured patient satisfaction using quantitative and qualitative methods.<sup>9,10</sup> We aimed to:

- describe epilepsy patients' knowledge of their condition;
- describe the social factors that predict the differences in people's knowledge of epilepsy;
- test the potential effect on knowledge levels of offering two appointments with a special epilepsy nurse; and
- test the potential effect of offering two appointments with a special epilepsy nurse on patients' emotional well-being.

## Method

In Stage 1, we identified a group of 283 people with active epilepsy who were registered with 37 general practitioners (GPs) in the South Thames region. The criteria for inclusion and exclusion have been described elsewhere.<sup>3</sup> We sent them a composite questionnaire that included a 'knowledge of epilepsy' questionnaire developed by Jarvie *et al.*<sup>11</sup> This questionnaire consists of 55 true/false questions with 34 medical items and 21 social items that had been tested in a hospital outpatient context in Scotland. The knowledge questionnaire was designed to measure important medical and social aspects of epilepsy derived from the medical literature and from experts in the field. It is available from the authors, or from Jarvie and his co-workers.

Our composite questionnaire also included the Hospital Anxiety and Depression (HAD) Rating Scale,<sup>12</sup> which has been demonstrated to have adequate sensitivity and predictive value in a general practice context.<sup>13</sup> A cut-off score point of eight on the anxiety and depression subscales has been found to yield the best

L Ridsdale, PhD, FRCPC, FRCGP, reader in general practice; and I Kwan, RGN, MSc, research associate, Division of General Practice and Primary Care, UMDS Guy's and St Thomas's Hospitals, London. C Cryer, PhD, senior lecturer in medical statistics; and the Epilepsy Care Evaluation Group (G Claridge, J Close, A Free, Y Hart, C Hughes, J Ogden, A Orme-Smith, N Stoy, P Stott, D Robins), South East Institute of Public Health, UMDS Guy's and St Thomas's Hospitals, Broomhill House, Tunbridge Wells.

Submitted: 16 July 1998; final acceptance: 18 December 1998.

© British Journal of General Practice, 1999, 49, 285-289.

compromise between sensitivity and false-positive rate when results using the questionnaire were compared with borderline cases and cases of anxiety and depression identified by the research interview for the Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM III).<sup>14</sup> General practice patients were sent the questionnaire on two occasions, approximately six months apart. In Stage 2, patients who returned a completed questionnaire on the first occasion were randomized so that approximately half were offered one appointment of 45–50 minutes with a special nurse at a 'neurology clinic' in their general practice and a follow-up appointment three months later. The items included in the intervention have been described elsewhere.<sup>8,15</sup> In practice, the nurse tailored the information and advice according to patients' needs, such as the need for advice on driving or contraception, for example, which vary from individual to individual. Where the nurse identified particular needs for information, she provided leaflets from a range of those provided by the British Epilepsy Association. We obtained ethics committee approval in each district included in the study.

### Statistical methods

The Student's *t*-test, the chi-squared test, and the Mann–Whitney U-test were used to compare the age, sex, seizure status, depression status, and knowledge scores for intervention and comparison groups at Stage 1, and to compare the 196 patients who responded at Stage 2 with the 55 patients who were sent questionnaires and failed to respond. Initial bivariate analysis was carried out to identify those variables that were associated with Stage 1 knowledge scores, and with the change in knowledge scores from Stage 1 to Stage 2, using Mann–Whitney U-tests and Kruskal–Wallis non-parametric one-way analysis of variance.<sup>16</sup> The variables investigated (age, age at leaving school, educational qualifications, and membership of self-help groups) were interrelated. To determine whether each of these variables was independently associated with Stage 1 knowledge score, or the change in knowledge score, we used unbalanced analysis of variance and multiple linear regression methods. This was achieved using the SPSS statistical software.<sup>17</sup>

Although the distributions of raw knowledge scores were skewed, the distribution of the residuals resulting from the analysis of variance and the regression analyses approximated to a normal distribution — a necessary assumption for the use of these techniques. At Stage 2, the proportions of people with a depression score greater than or equal to eight, in both the intervention and control groups, were compared using the chi-squared test. Additionally, a comparison was made while controlling for depression status at Stage 1 using the Mantel–Haenszel method.<sup>18</sup> This method is often used and is an accepted method for carrying out a stratified analysis to adjust for a confounding variable within an analysis. Data were not available for all characteristics for all patients, therefore the relevant denominator is provided.

## Results

### Response rates

Two hundred and fifty-one (89%) patients returned the completed questionnaire at the first stage. These responders were randomized so that 127 were offered two appointments three months apart with a special nurse; 106 (83%) attended. Between Stage 1 and Stage 2 (follow-up assessment by questionnaire), 16 patients were lost to follow-up: 11 patients moved away, three died, and two were withdrawn by GPs or carers because of an illness that met the exclusion criteria for the study.<sup>3</sup> Of these 16, seven were in the intervention group and nine were in the control

group. At Stage 2, 235 patients were in the study, and complete datasets with returned questionnaires on two occasions, before and after the intervention, were available for 100 people in the intervention group and 96 in the control group.

The intervention and comparison groups were not significantly different in terms of age, sex, epilepsy attacks, knowledge scores, and depression status in the six months prior to Stage 1. The 196 patients who responded at Stage 2 were not significantly different from the 55 non-responders in terms of age, sex, epilepsy attacks in the previous six months, knowledge score, and depression status at Stage 1. Those who attended the intervention (106) and those who did not (21) were not significantly different with respect to these characteristics also.

### Patient's knowledge about their condition

First, we compared our 251 general practice patients in terms of knowledge of epilepsy scores with two groups of hospital outpatients seen in Scotland<sup>10</sup> and England.<sup>19</sup> We used the median as a measure of central tendency, as the frequency distribution of knowledge scores was skewed. Overall, patients' knowledge scores were remarkably similar in Scotland and England, and in hospital or general practice. This is shown in Table 1.

### Social factors associated with greater or lesser knowledge of epilepsy

In the initial bivariate analysis, patients' age, school-leaving age, educational qualifications, and membership of self-help groups were associated with knowledge at Stage 1. We found that median knowledge of epilepsy scores were significantly higher in younger people, as shown in Table 2. Responders' school-leaving age ranged from less than 14 to 19 years, and their median knowledge scores ranged from 37 to 45, with later school-leaving age being significantly associated with higher median knowledge scores ( $P = 0.0001$ , Kruskal–Wallis test). Responders provided details of their qualifications: 115/251 (46%) had passed General Certificate Examinations, GCSEs, or had higher qualifications; 87/251 (35%) had no qualifications; and the remaining 38/251 (15%) had qualifications that could not be classified. People with the equivalent of GCSEs or higher had significantly higher knowledge of epilepsy scores than those with no formal qualifications (43 versus 39;  $P \leq 0.001$ , Mann–Whitney U-test). Higher knowledge score was also associated with higher occupational class, but this relationship was weaker than for other social factors.

We found that only a small subgroup of 17/245 (7%) patients were members of a self-help group. This group had a median total knowledge of epilepsy score that was significantly higher (45 versus 42;  $P = 0.0003$ , Mann–Whitney U-test) than the remaining 228/245 (93%) who did not belong to a self-help group.

As the social characteristics were associated with one another in bivariate analyses, a particular social variable's association with knowledge is potentially confounded by the other social variables. To determine whether each of the variables were independently associated with knowledge scores, we used unbalanced analysis of variance and multiple linear regression methods. Results are shown in Table 3. Sex and occupational class were also investigated and we found no independent association with knowledge levels. In summary, younger age, older age at leaving school, the possession of GCSEs and above, and membership of a self-help group were each independently associated with higher knowledge of epilepsy scores.

### Knowledge of epilepsy before and after the intervention

To test the hypothesis that seeing a nurse might change knowl-

**Table 1.** Social variables and knowledge scores of people with epilepsy seen in hospital outpatients and general practice.

	Outpatients (Glasgow)	Outpatients (London)	General practice (South Thames: the study population)
Number in population	82	70	251
Percentage of males	47	38	54
Percentage of females	53	61	46
Mean age in years (range)	33 (16–75)	42 (18–76)	51 (17–90)
Total knowledge score (median)	43	42	42
Medical knowledge (median)	27	27	26
Social knowledge (median)	16	15	15

**Table 2.** The association between age and knowledge of epilepsy scores.

Knowledge score	Age group (years)				Kruskal–Wallis P-value
	17–37 (n = 39)	38–51 (n = 85)	52–64 (n = 66)	65+ (n = 61)	
Total (median)	43	43	42	37	<0.001
Medical	28	27	27	23	<0.001
Social	16	15	15	14	0.015

**Table 3.** Multiple regression of total knowledge scores and social characteristics.

Variable	n	Median scores	Estimated difference <sup>a</sup>	F-value	Degrees of freedom	P-value
Age (years) <sup>a</sup>						
17–37 <sup>c</sup>	39	43	0	9.44	3, 235	<0.001
38–51	82	43	0.06			
52–64	62	42	–0.40			
65+	58	37	–5.34			
School-leaving age <sup>a</sup>						
≤16 <sup>c</sup>	139	40	0	7.47	1, 235	0.007
>16	102	43	2.33			
Qualifications <sup>b</sup>						
None <sup>c</sup>	86 <sup>d</sup>	39	0	13.91	1, 194	<0.001
GCSE or above	114 <sup>d</sup>	43	3.23			
Membership of self-help group <sup>a</sup>						
Non-member <sup>c</sup>	224	42	0	8.94	1, 235	0.003
Member	17	45	4.89			

<sup>a</sup>The effects were estimated from a model that included the independent variables: age, school-leaving age, and membership of a self-help group.

<sup>b</sup>The effects were estimated from a model that included the independent variables: age, qualifications, and membership of a self-help group.

<sup>c</sup>Reference category for the estimated differences. <sup>d</sup>The number of observations used to estimate the effect of 'Qualifications' is equal to 200, mainly due to the number of missing values for this variable. <sup>e</sup>Estimated differences between the category shown and the reference category adjusting for the other independent variables in the model.

edge levels, we analysed knowledge scores for the intervention and comparison groups at Stage 1 and Stage 2. Overall we found no change. When we analysed subgroups according to the age at which they had left school, we found that there was a trend towards the group who had left school earlier, and who had a lower median total knowledge of epilepsy score, gaining more knowledge. However, adjustment would need to be undertaken for multiple comparisons and, allowing for this, there is no significant effect.

### *Depression scores before and after the intervention*

*Seizure in the past six months.* In 1996, we reported that the risk of depression status was significantly related to whether patients had experienced an attack of epilepsy in the previous six months.<sup>4</sup> We therefore analysed for the effect of the intervention on patients separately according to whether they reported having an attack in the previous six months. For those patients who had

experienced an epilepsy attack in the previous six months, we found no significant difference between the risk of depression for the group randomized to the nurse clinic compared with the control group; this is illustrated in Table 4.

*No seizure in the past six months.* For patients who had no seizure prior to Stage 2, the risk of depression was significantly less for the group randomized to the nurse-run clinic compared with the control group ( $P = 0.03$ ). This result was also obtained when controlling for baseline risk of depression, and is shown in Table 4. For the group who had not had a seizure in the previous six months, the risk of depression for those in the intervention group was 6% compared with 19% for those in the control group; this is a third of the risk. The number of high scorers in the control group increased between Stage 1 and Stage 2, while the scores for those randomized to see the nurse tended to improve. The originators of the HAD used the cut-off scoring



**Table 4.** Relative risk of depression in the intervention and comparison groups for patients with and without epilepsy attacks in the previous six months.<sup>a</sup>

	Stage 1 n (%)	Stage 2 n (%)	c <sup>2</sup>	P-value	RR <sup>c</sup>	95% CI
Seizure <sup>b</sup>						
Control	8/29 (28)	7/30 (23)	0.59	0.44	0.72	0.32–1.65
Intervention	8/31 (26)	10/31 (32)				
No seizure						
Control	5/60 (8)	12/62 (19)	4.98	0.03	3.15	1.15–8.60
Intervention	9/64 (14)	4/65 (6)				

<sup>a</sup>Data were not available for all characteristics for all patients, so the relevant denominator is provided. <sup>b</sup>Seizure in the six months prior to Stage 2.

<sup>c</sup>RR is the estimated ratio of the risk of depression in the control patients relative to the intervention patients at Stage 2.

method<sup>12</sup> and this has been conventionally applied.

We also compared median depression scores for all patients randomized to the intervention and the control group, and separately for people who had or did not have recent epilepsy attacks. At Stage 2, the median depression score of all patients in the intervention group was significantly lower than the score in the control group ( $P = 0.024$ , Mann-Whitney U-test). When scores were analysed by seizure status, this effect was largely attributable to differences in the group of patients (124) who reported no recent epilepsy attack.

## Discussion

People with epilepsy report that they have been provided with too little information and support.<sup>1,2</sup> We aimed to describe a group of people with epilepsy in general practice, to describe the extent to which social and medical characteristics were related to their knowledge and emotional status, and to test the potential effect of a nurse input on their knowledge and emotional state. We found that younger people, those who had remained in education longer, and those who belonged to self-help groups had significantly higher knowledge of epilepsy scores. The benefit of belonging to a self-help group was independent of educational status. Only 10% of this group had reported that they had been told about self-help groups and only 7% belonged to them.<sup>3</sup> It will be important for doctors and other health education providers be aware of and address these differences in knowledge when planning and providing advice. Older people, those who left school earlier or with no qualifications, and those who do not belong to self-help groups may require more help in learning to manage their condition. These social determinants of knowledge are particularly relevant because the cumulative incidence of epilepsy is highest in elderly people.<sup>20</sup> Recommending that patients join self-help groups may have an incremental benefit.

There was a trend towards increased knowledge of epilepsy scores in the patients who had lowest knowledge levels prior to the intervention, but the intervention of a nurse did not change knowledge scores overall. There are many possible explanations for this. The average duration of epilepsy for patients in this community-based group was 23 years (range 2–79 years). During this time they had acquired information from many sources, and some expressed the view that this intervention would have helped them most had it been provided earlier on in their illness.<sup>15</sup> While the knowledge questionnaire we employed was designed to measure important medical and social aspects of epilepsy, it was not specifically designed to test the intervention of a special nurse. There is also a possibility that some of the non-significant results could be because of a lack of statistical

power in the comparisons, owing to the modest study size, particularly in subgroup analysis.

The majority of patients did not report an epilepsy attack in the previous six months. At Stage 2, those in this subgroup who were randomized to the nurse input had a third of the risk of depression compared with the control group. Patients who reported an epilepsy attack in the six months prior to the intervention had three times the risk of high depression scores at Stage 1.<sup>4</sup> Randomization to the nurse intervention did not reduce the risk of depression in the patients who had had a seizure in the previous six months. The positive effect on depression status for patients with no recent epilepsy attack is consistent with the positive satisfaction scores and comments when a subsample were interviewed by Scambler *et al.*<sup>9</sup> Guidelines have recently been published on the management of poorly controlled epilepsy,<sup>21</sup> as has a review of the evidence on the effectiveness of psychological interventions for this group.<sup>22</sup> If they could achieve a health gain, this might prevent a vicious cycle of social handicap and disadvantage in the future.

## References

1. British Epilepsy Association. *Towards a new understanding*. Leeds: British Epilepsy Association, 1990.
2. Scambler G. *Epilepsy*. London: Routledge, 1989.
3. Ridsdale L, Robins D, Fitzgerald A, *et al.* Epilepsy monitoring and advice: general practitioners' views, current practice and patients' preferences. *Br J Gen Pract* 1996; **46**: 11–14.
4. Ridsdale L, Robins D, Fitzgerald A, *et al.* Epilepsy in general practice: patients' psychological symptoms, and their perception of stigma. *Br J Gen Pract* 1996; **46**: 365–366.
5. Taylor MP. Epilepsy in a Doncaster practice: audit and change over eight years. *J R Coll Gen Pract* 1987; **37**: 116–119.
6. Jacoby A, Baker GA, Steen N, *et al.* The clinical course of epilepsy and its psychosocial correlates: findings from a UK community study. *Epilepsia* 1996; **37**(2): 148–161.
7. Shorvon SD, Dellaportas CI, Goodridge DMG, Bradbury C. *The clinical nurse specialist in epilepsy*. Chalfont St Peter: National Society for Epilepsy, 1993.
8. Ridsdale L, Robins D, Cryer C, *et al.* Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial. *BMJ* 1997; **314**: 120–122.
9. Scambler A, Scambler G, Ridsdale L, Robins D. Towards an evaluation of an epilepsy nurse specialist in primary care. *Seizure* 1996; **5**: 255–258.
10. Ridsdale L, Morgan M, O'Connor C. Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse. *Patient Educ Counsel* 1999; **37**(1): 43–47.
11. Jarvie S, Espie CA, Brodie MJ. The development of a questionnaire to assess knowledge of epilepsy. 1. General knowledge of epilepsy. *Seizure* 1993; **2**: 179–185.
12. Zigmund AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; **67**: 361–370.
13. Wilkinson MJB, Barczak P. Psychiatric screening in general practice: comparison of the general health questionnaire and the hospital anxiety depression scale. *Br J Gen Pract* 1988; **312**: 311–313.

14. American Psychiatric Association Committee of Nonmenclature and Statistics. *Diagnostic and statistical manual of mental disorders*. 3rd edition. (DSM III.) Washington DC: American Psychiatric Association Press, 1980.
15. Ridsdale L. Diagnosis and care of epilepsy. *Practitioner* 1997; **241**: 528-533.
16. Altman DG. *Practical statistics for medical research*. London: Chapman & Hall, 1991.
17. Norusis MJ. *The SPSS guide to data analysis for release 4*. Upper Saddle River, NJ: Prentice-Hall, 1990.
18. Mantel N, Haenszel W. Statistical aspects of the analysis of data from retrospective studies of disease. *J Natl Cancer Inst* 1959; **22**: 719-748.
19. Goldstein LH, Minchin L, Stubbs P, Fenwick PBC. Are what people know about their epilepsy and what they want from an epilepsy service related? *Seizure* 1997; **6**: 435-442.
20. Chadwick D. Epilepsy. In: Wiles CM (ed). *Management of neurological disorders*. London: BMJ Publishing Group, 1995.
21. Royal College of Physicians, Institute of Neurology, National Society for Epilepsy. *Adults with poorly controlled epilepsy*. London: Royal College of Physicians, 1997.
22. Goldstein LH. Effectiveness of psychological interventions for people with poorly controlled epilepsy. *J Neurol Neurosurg Psychiatry* 1997; **63**: 137-142.

### Acknowledgements

We are grateful for funding from the Nuffield Provincial Hospitals Trust, to the NHSE South Thames Regional Office and James Ditchburn who provided statistical support, to the British Epilepsy Association, and the National Society for Epilepsy.

### Address for correspondence

Dr Leone Ridsdale, Division of General Practice and Primary Care, UMDS Guy's and St Thomas's Hospitals, 5 Lambeth Walk, London SE11 6SP.