

# Non-compliance with treatment by epileptic patients at George Provincial Hospital

**Krause SR**, MFamMed

Department of Family Medicine, Faculty of Health Sciences, University of the Free State, Bloemfontein

**Van Rooyen FC**, MCom

Department of Biostatistics, Faculty of Health Sciences, University of the Free State, Bloemfontein

**Van Vuuren MVJ**, MPraxMed, PhD

Department of Family Medicine, Faculty of Health Sciences, University of the Free State, Bloemfontein

**Jenkins L**, MFamMed

Family Medicine Department, George Provincial Hospital and Stellenbosch University

**Correspondence to:** FC van Rooyen, e-mail: gnbsfcvr.md@mail.uovs.ac.za

## Abstract

### Background

Non-compliance with anti-epileptic drug treatment in the George area, resulting in recurrent seizures and visits to the emergency department of the George Provincial Hospital, has been identified as a social and economic problem. The aim of this study was to determine the socio-economic and medical factors, the information given to patients by healthcare workers, and the understanding of patients living with epilepsy who presented to the emergency department with seizures.

### Methods

A descriptive study design was employed and the data-collection tools were a questionnaire and structured interview.

### Results

The median age of the study population was 32 years. The patients had suffered from epilepsy for a median of two years and visited a clinic for a median of seven times a year. The median education level was primary school and three quarters had no employment or government grant. The majority did not understand the disease, the side effects of the medication and why they should be on medication. In addition, it became apparent from patient reports that healthcare workers showed a lack of counselling skills, time and appropriate knowledge.

### Conclusions

There is a general lack of understanding of epilepsy by the patient. Not only were the patients uninformed, but they also showed apathy towards the management of their condition.

**SA Fam Pract 2007;49(9):14**

**Introduction**

The effect of recurrent epileptic seizure attacks on the patient is far reaching. Poor compliance may lead to status epilepticus, as well as unexpected, sudden death.<sup>1,2</sup> Recurrent convulsions can reduce the likelihood of eventually curing the disorder.<sup>3</sup>

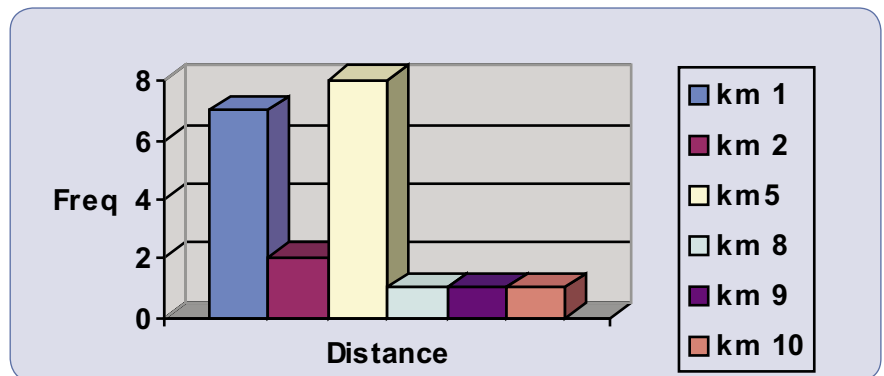
With appropriate treatment and lifestyle changes, the majority of patients diagnosed with epilepsy will become seizure-free. Compliant behaviour can be defined as taking anti-epileptic drugs (AEDs) on time and without fail, not manipulating dosages, and following the doctor's advice regarding daily activities.<sup>4</sup> Non-compliance is a significant problem in epilepsy management. As many as 30% to 50% of persons with epilepsy are non-compliant to the extent of interfering with their optimal treatment.<sup>4</sup> The effect of non-compliance is enormous and may lead to an increase in the number of seizures, medical costs and injury to themselves and others.<sup>5</sup>

Patient education stands out as one of the most important aspect to improve compliance.<sup>6</sup> The method of education depends on the population. First-world methods are not applicable in rural South Africa. In a study done in Zimbabwe, patient information pamphlets neither influenced the seizure frequency nor patients' understanding of the disease.<sup>7</sup> In India, a study relating to doctor-patient communication and compliance stated that compliance improved when patients were satisfied with the consultation process and were asked to recall the information. Multiple visits to the doctor enhanced communication, and thus compliant behaviour.<sup>5</sup>

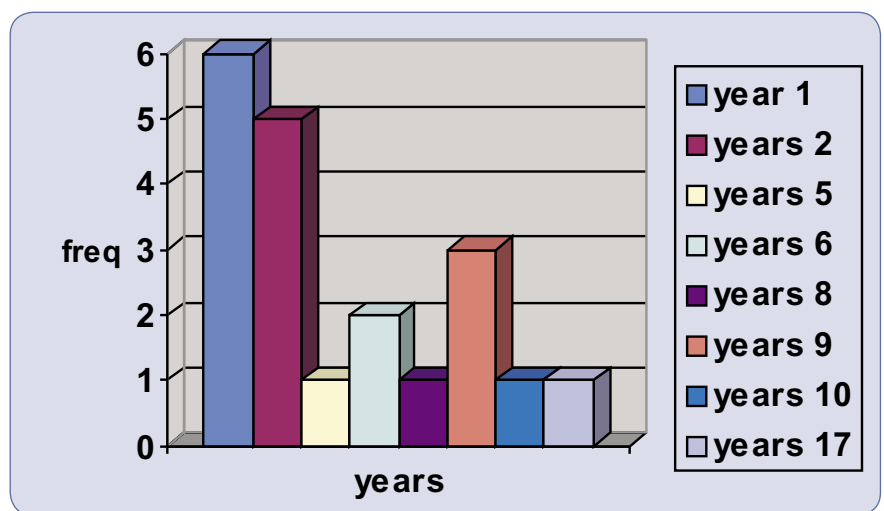
George Hospital is the regional hospital in the Southern Cape and serves a population of 500 000. The staff-to-patient ratio at the emergency department (ED) during the day is one professional nurse to 21 patients (personal communication, Ms H Langenhoven, Unit Nursing Manager). Against this background of a poor patient/staff ratio, it is essential that non-compliant epileptic patients are treated and counselled at the primary level in order to keep their ED visits to a minimum.

No substantial information could be found regarding recurrent visits to the ED by patients with epileptic seizures in South Africa. This study determined the medical and socio-economic factors, the information given to patients by healthcare workers and the understanding of epileptic patients with seizures

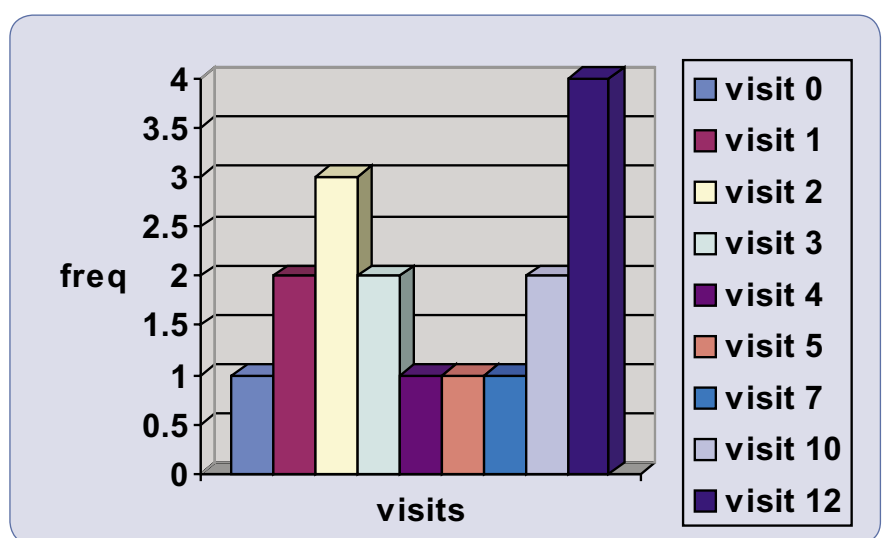
**Figure 1:** Distance travelled to clinic



**Figure 2:** Duration of the patients' epilepsy



**Figure 3:** Number of visits to clinic



that impact on recurrent visits to the ED of George Provincial Hospital.

**Methods**

This descriptive study included 21 consecutive epileptic patients with seizures admitted to the ED of George Provincial Hospital between 1 December 2004 and 16 April 2005. Male and female patients, 16 years and older, who had been di-

agnosed with epilepsy at least one year previously, were included. Patients who were not able to respond to an interview were excluded.

The data-collection tools were a questionnaire and a structured interview. The questionnaire included both open-ended and closed questions. Patients who repeatedly visited the ED during the study period were only in-

interviewed once. The questionnaire was used as a guide during the interview. The first author completed the questionnaires where possible; however, the doctor on duty occasionally assisted with the interviews.

Descriptive statistics, namely medians and percentiles, were calculated for continuous data. Frequencies and percentages were calculated for categorical data.

Three patients took part in a pilot study, after which the questionnaire was amended accordingly. Participants gave written informed consent after the purpose of the study had been explained to them. The Ethics Committee of the Faculty of Health Sciences, University of the Free State approved the study.

## Results

Twenty-one patients took part in the study. Their ages ranged from 17 to 71 years (median 32 years), and most were male (76.2%). The point of care for most patients was a clinic (95.2%), and one patient saw a general practitioner (4.8%). No patient visited a specialist.

The distances travelled between the patients' homes and the clinic are given in Figure 1. The median distance between the patients' homes and the clinic was 5 km. Nineteen patients (90.5%) walked to the clinic. Eighteen patients (85.7%) made use of the hospital ambulance for transport to the ED. Most patients (65%) had a primary school education and four (20%) had high school education, while 10% had no formal education. Sixteen patients (76.2) were unemployed and received no government grant.

The duration for which the patients had epilepsy is given in Figure 2. The patients' median period of being diagnosed with epilepsy was two years. Patients had a median seizure frequency of one per month, and half of the patients had a seizure frequency of one per month. Forty per cent had a seizure frequency of one every six months and 10% a seizure frequency of once a year. Most patients (95.2%) visited a clinic for their medication a median of seven times a year. The number of visits to the clinic is given in Figure 3. (All information was obtained through patient recall (see first two paragraphs under methods))

The information given to the participants by clinic healthcare workers is given in Table I. Two-thirds (66.7%) of the patients said that no healthcare

**Table I:** Information given to participants by clinic healthcare workers (n = 21)

|  |     | Frequency | Percentage |
|--|-----|-----------|------------|
| Described disease  | Yes | 7         | 33.3       |
|  | No  | 14        | 66.7       |
| Described cause of disease   | Yes | 3         | 14.3       |
|  | No  | 18        | 85.7       |
| Described epilepsy treatment   | Yes | 7         | 33.3       |
|  | No  | 14        | 66.7       |
| Described disease management for comfortable life                    | Yes | 4         | 19.1       |
|  | No  | 17        | 80.9       |
| Used understandable terms  | Yes | 6         | 28.6       |
|  | No  | 15        | 71.4       |
| Explained usefulness of anti-epileptic drugs in controlling seizures | Yes | 10        | 47.6       |
|  | No  | 11        | 52.4       |
| Explained adverse effects of anti-epileptic drugs                    | Yes | 1         | 4.8        |
|  | No  | 20        | 95.2       |
| Adverse effects suffered as reported by patients                     | Yes | 0         | 0          |
|  | No  | 21        | 100        |
| Informed of seizure control likelihood and epilepsy cure             | Yes | 0         | 0          |
|  | No  | 21        | 100        |

**Table II:** Patients' lifestyles and information given by clinic healthcare workers regarding lifestyle modification

|  |         | Frequency | Percentage |
|--|---------|-----------|------------|
| Do you drive (n = 21)                    | Yes     | 0         | 0          |
|  | No      | 21        | 100        |
| Informed of risk of driving (n = 20)     | Yes     | 2         | 10         |
|  | No      | 18        | 90         |
| Informed of regular food intake (n = 21) | Yes     | 4         | 19.0       |
|  | No      | 17        | 81.0       |
| Alcohol intake (units per week) (n = 17) | 1       | 4         | 23.5       |
|  | 2       | 5         | 29.4       |
|  | 3       | 1         | 5.8        |
|  | 4       | 2         | 11.8       |
|  | 5       | 2         | 11.8       |
|  | Lots    | 2         | 11.8       |
|  | Unknown | 1         | 5.8        |
| Told to avoid alcohol (n = 21)           | Yes     | 11        | 52.4       |
|  | No      | 10        | 47.6       |

worker had described their disease and only 14.3% of the patients indicated that they had been told what the cause of their disease was. Healthcare workers explained the usefulness of AEDs in controlling seizures and the adverse effects of AEDs to 47.6% and 4.8% of the patients respectively.

Information about the patients' lifestyles and the information given by the clinic

healthcare workers regarding lifestyle modification are given in Table II. A fifth (19.0%) of the patients were informed of regular food intake and 52.4% were told to avoid drinking alcohol, while 11.1% of the patients admitted to drinking excessively.

The patients' compliance with their treatment and understanding of their disease are given in Table III. More than

**Table III:** Patients' compliance with treatment and understanding of their disease (n = 21)

|   |          | Frequency | Percentage |
|---|----------|-----------|------------|
| Do you take your anti-epileptic drug regularly and on time?             | Yes      | 9         | 42.9       |
|   | No       | 12        | 57.1       |
| Can you miss your doses if you have been seizure free for a few months? | Yes      | 6         | 28.6       |
|   | No       | 15        | 71.4       |
| How do you understand your disease?                                     | Positive | 5         | 24         |
|   | Negative | 16        | 76         |
| How do you understand your treatment?                                   | Positive | 12        | 57         |
|   | Negative | 9         | 43         |
| How do you understand your prognosis?                                   | Positive | 8         | 14         |
|   | Negative | 18        | 86         |
| Who is responsible for your treatment?<br>(n = 20)                      | Doctor   | 2         | 10         |
|   | Sister   | 1         | 5          |
|   | Family   | 6         | 30         |
|   | Yourself | 11        | 55         |

half (57.1%) of the patients indicated that they did not take their AEDs regularly. Many (57.1%) patients thought that if they had not had a seizure for a period of time they were cured. Only five patients (24.0%) indicated a sufficient understanding of their disease. Nine patients (43%) had no understanding of how to treat their disease. Most patients indicated a negative understanding of their disease (76.0%) and prognosis (86%). Only 52.4% of the patients felt that they were responsible for their own treatment.

### Discussion

Most of the patients (95.2%) relied on the local clinic for their medication and any other form of intervention. This indicated what an important role the primary healthcare clinic plays in the George area. Most patients had to walk to the clinic and had to rely on hospital transport (ambulance) when they had a seizure. This remains a major problem for effective health care, because there are only three equipped ambulances serving this area. Epileptic patients are often unconscious from a seizure and are classified as priority 1 patients requiring immediate transport.

A handout with information on epilepsy and its management would probably not be effective, because most of the patients had only a primary school education. For any meaningful counselling to take place, the healthcare workers would have to be specifically trained and have sufficient time at their disposal to verbally inform patients about their

condition and the consequences of non-compliance. The majority of the patients had been diagnosed with epilepsy for a median period of two years, which should have allowed sufficient time for counselling or information on changing their lifestyles.

In George, most non-compliant epileptic patients are transported to the ED by ambulance, are often accompanied by a family member and stay in the hospital overnight. In contrast, more than 50% of patients in Baltimore with seizures are transported by ambulance and stay in the ED for approximately four hours.<sup>8</sup>

Many of the patients who visit the George ED with recurrent seizure problems have no form of income and few receive a government grant. A similar problem was found in a study conducted in America, where patients with recurrent seizures (61%) were indigent and had no regular source of income or access to regular primary health care.<sup>8</sup>

According to Van der Meyden and Rodda, the criteria for adequate epilepsy control mainly include whether the occurrence of seizures or the side effects of AED are considered by the doctor/patient to be prohibitive of a reasonable and normal lifestyle.<sup>9</sup> In this study, the patients had a median of one seizure per month. This occurrence will affect their lifestyles, particularly if it includes spending the night in the ED.

The patients visited their clinics a median of seven times a year. The clinics only issue one month's treatment with each visit. This indicates non-compliance with the treatment regime. As seen

in Zimbabwe<sup>7</sup> and India,<sup>5</sup> recurrent visits and good doctor-patient communication remain the cornerstone of compliance.

Two-thirds of the patients indicated that healthcare workers had not spoken to them about their disease. Consequently, they did not know why they had to take the tablets. This could indicate that the healthcare workers did not understand the disease themselves, or lacked confidence in the treatment of epilepsy. However, this is from the patients' perspective and a study of the healthcare workers' knowledge and attitudes towards epilepsy would be interesting.

Most patients did not know how to treat their disease. In these instances, the interviewer tried to ascertain whether the patients knew that they had to take tablets to manage their epilepsy. Taking into account the severity of status epilepticus, the risk of sudden death and the side effects of AEDs, it is worrying that these patients were not counselled about their AED treatment. Patients did not receive counselling about lifestyle modifications and did not understand the basic approach to their condition, for example the need for regular intake of medication and food.

Most patients concluded that they understood what the healthcare worker said. However, the healthcare workers did not tell them why they had seizures or how to treat their seizures, or how to change their lifestyle to live a seizure-free life. The patients' prognosis was also not discussed with them. Approximately half of the patients knew that AEDs were useful in order to be free of seizures. However, the patients who did know that they must take their medication were still non-compliant, indicating that lack of self-care is an obstacle to compliance. Most patients were not told of the adverse effects of AEDs, or that the tablets must be taken carefully to prevent lethal toxic effects.

Only four patients (19.0%) knew how important regular meal intake was. Hypoglycaemia is a major factor among epileptic patients, and can precipitate a seizure, making it essential for patients to eat at regular intervals. Few (11.8) of the patients admitted that they drink a lot of alcohol. The possibility of good compliance is one of the criteria for starting AEDs. Alcohol abusers eat poorly, forget to take their tablets and are unreliable patients who tend to display poor compliance with taking AEDs. More than half of the patients (57.1%)

did not know that it was essential that they take their medication at regular intervals. This is one of the reasons for patients with low drug levels saying that they have taken their tablets, but they neglect to say that the tablets are taken haphazardly and at irregular intervals. Few of the patients had an understanding of their disease and 43% did not understand their treatment. This is probably the main reason for non-compliance. Only half the patients made the responsibility of the disease and its treatment their own. It must be noted that the study looked at epileptic patients presenting at an ED with seizures and they therefore are a subset of epileptic patients.

### Conclusion

There is a general lack of understanding of epilepsy by these patients. Not

only were the patients poorly informed, but they also showed apathy towards the management of their condition. In addition, the patients indicated that healthcare workers did not spend sufficient time and effort in counselling and informing them and discussing their illness with them. This suggests a lack of counselling skills, time and appropriate knowledge. Hence, non-compliance in epileptic patients is a complex problem that needs intervention from both the patient and the primary healthcare worker's side.

### References

1. Mawdsley C, Simpson JA. Diseases of the nervous system. In: MacLeod J, editor. Davidson's principles and practice of medicine. 13th edition. Edinburgh: Churchill Livingstone; 1981. p. 649–748.
2. Jay GW, Leestma JE. Sudden death in epilepsy. A comprehensive review of the literature and proposed mechanisms. *Acta Neurol Scand* 1981;63(suppl):1–66.
3. Shorvon SD, Reynolds EH. Early prognosis of epilepsy. *BMJ* 1982;285:1699–701.
4. Leppik IE. How to get patients to take their medicine. *Postgrad Med* 1990;88(1):253–5.
5. Gopinath B, Radhakrishnan K, Jayachandran D, Alexander A. A questionnaire survey about doctor-patient communication, compliance and locus of control among South Indian people with epilepsy. *Epilepsy Research* 1999;(39):73–82.
6. Winnick S, Lucas DO, Hartman AL, Toll D. How do you improve compliance? *Pediatrics* 2005;(115):716–24.
7. Adamolekun B, Mielke JK, Ball DE. An evaluation of the impact of health worker and patient education on the care and compliance of patients with epilepsy in Zimbabwe. *Epilepsy* 1999; 40(4):507–11.
8. Krumholz A, Grufferman S, Orr ST, Stern BJ. Seizures and seizure care in an emergency department. *Epilepsy* 1998;30(2):175–180.
9. Van der Meyden CH, Rodda JL. Epilepsy management at primary health care level – guideline. *SAMJ* 2000;90(4):423–32.