

Clinical Research

An Assessment of Epilepsy Patients' Knowledge of Their Disorder

Lucretia Long, Andrew L. Reeves, J. Layne Moore, Jessica Roach, and Carolyn T. Pickering

Department of Neurology, The Ohio State University College of Medicine, and The Ohio State University College of Pharmacy, Columbus, Ohio, U.S.A.

Summary: *Purpose:* Patient education is an effective component of comprehensive care. Studies assessing patient's knowledge of their epilepsy are scarce. We report the first objective study evaluating knowledge of epilepsy patients referred to an American tertiary care center.

Methods: Two hundred twenty epilepsy patients referred to an epilepsy center completed a knowledge questionnaire. The questionnaire included topics related to safety, compliance, and legal issues of driving and employment. Questionnaire scores were correlated with demographics, number of years with epilepsy, and educational background.

Results: Of 220 patients, 175 were included in study analysis. Thirteen percent ($n = 28$) were excluded because of the diagnosis of nonepileptic seizures, and 8% ($n = 17$) were excluded because of having a diagnosis other than epilepsy. The average age and number of years with epilepsy was 34.7 ± 13 and 14.4

± 13.1 , respectively. Neither age ($r = 0.20$, $p \leq 0.01$), number of years with epilepsy ($r = 0.09$, $p = 0.2$), nor years of education ($r = 0.34$, $p \leq 0.01$) correlated with questionnaire scores. Thirty percent believed that epilepsy is a mental disorder or contagious. Forty-one percent believed it is appropriate to place an object in a patient's mouth during a seizure to prevent injury. Two of the lowest scores, 13.6% and 47.5%, pertained to the legal issues of driving and employment, respectively.

Conclusions: Patients with epilepsy are not knowledgeable about their disorder. This is true regardless of age, educational background, or number of years with epilepsy. There is a need for educational intervention in this population, particularly related to injury prevention and the legalities of driving and employment. **Key Words:** Epilepsy—Questionnaire—Knowledge—Education—Counseling.

Patient education is a necessary component of quality care. Although seizure control is the mainstay of epilepsy treatment, patients must be educated on the daily management and prevention of seizures. Investigators have assessed self-management procedures in patients with epilepsy (1), patients' preference of who should educate them (2), and health care professionals' perspectives on what should be taught (3,4). Although patient education is critical, limited data are available assessing what patients with epilepsy actually know about their disorder.

Dawkins et al. (5) compared the knowledge and attitudes of epilepsy among patients with the disorder with those of persons without it. Patients were identified from general practices in southwest London and Surrey. The

questionnaire for patients with epilepsy focused on treatment, home circumstances, social effects of epilepsy, employment, and driving. Results indicated that epilepsy patients knew little more about their disorder than did those without epilepsy. In a similar study conducted in the United Kingdom (6), patients without epilepsy demonstrated greater knowledge of medical aspects of epilepsy than did those with the disorder. A study conducted in South Thames, England, concluded that 35% of epilepsy patients felt they were not receiving adequate information about their disorder (7). Goldstein et al. (8) indicated that epilepsy patients in an English tertiary care center were unaware of knowledge concerning seizure type and indications for anticonvulsant drug (AED) therapy. More than 25% of patients in this study reported incorrect information concerning their AED regimen. A variety of studies in different countries have evaluated certain aspects of epilepsy patient education. No published objective data assess the knowledge of American epilepsy patients referred to a tertiary care center.

Accepted January 26, 2000.

Address correspondence and reprint requests to Ms. L. Long at The Ohio State University, Department of Neurology, 1654 Upham Drive, 416 Means Hall, Columbus, OH 43210-1250, U.S.A. E-mail: long.278@osu.edu

TABLE 1. Patient demographics

Total	175
Female	98
Male	77
Mean age	34 ± 13 yr
Epilepsy diagnosis	14 ± 13 yr

METHODS

An Epilepsy Patient Knowledge Questionnaire (EPKQ) was developed and distributed to newly referred patients at The Ohio State University Medical Centers' Comprehensive Epilepsy Program. The three-page, 13-item questionnaire included a variety of multiple-choice, true and false, and "fill in the blank" questions. The questionnaire focused on defining epilepsy ($n = 1$), safety ($n = 3$), medication compliance ($n = 4$), social activities ($n = 1$), and the legal issues of driving ($n = 2$) and employment ($n = 2$). The questionnaire contents were determined by epilepsy experts, emphasizing common topics associated with this condition. Demographics, number of years with epilepsy, and education level also were recorded. Education levels were collected in categories.

Before distribution, the hospital Patient Education Coordinator reviewed the questionnaire for simplicity, readability, content, and formatting. The questionnaire was evaluated by epilepsy experts and pilot tested by 15 patients to eliminate questions that were potentially misleading or difficult to comprehend. Inclusion criteria included a diagnosis of epilepsy, the ability to read and write English, and being physically capable of completing the questionnaire. Only patients aged 16 years or older were included in data analysis. Whereas the EPKQ was administered to all patients referred with the diagnosis of seizures, to eliminate bias, only patients with the diagnosis of epilepsy after evaluation were included in study analysis. Patients with nonepileptic seizures (NES) and those with a single seizure were excluded. Established epilepsy was confirmed by clinical presentation, electroencephalograms, and magnetic resonance imaging studies. Questionnaires of patients with NES were excluded retrospectively, after epilepsy monitoring unit evaluations. Because the knowledge questionnaire was used clinically to guide education interventions, the institution did not require Internal Review Board (IRB) approval. Statistical analysis was performed by using Pearson's correlation coefficient, Student's t test, and Fisher's Exact Test with $\alpha = 0.05$. Questionnaire scores were calculated in percentages.

RESULTS

Of the 220 questionnaires, 45 (20%) were excluded, because either of the diagnosis of NES ($n = 28$) or being diagnosed with a disorder other than epilepsy ($n = 17$).

TABLE 2. Years of formal education

23% ($n = 40$)	<12
37% ($n = 65$)	12
40% ($n = 60$)	>12

Demographics are summarized in Table 1. Formal years of education are summarized in Table 2. There were two patients from a different country in which formal education is not universal. Data on socioeconomic status were not collected. Neither age ($r = 0.20$, $p < 0.01$), number of years with epilepsy ($r = 0.09$, $p < 0.2$), nor years of education ($r = 0.34$, $p < 0.01$) correlated with correct questionnaire scores. Figures 1, 2, and 3 provide scatterplot diagrams of these findings. The mean total correct score for each item is summarized in Appendix 1. The percentage correct for male and female patients were similar, 57 and 58%, respectively. Fifty-three (29.9%) patients believed that epilepsy is a mental disorder or a disease that is contagious. The total mean scores on questions related to compliance and safety were 84.7 and 57.5%, respectively. Only 31.6% of patients responded correctly to the question concerning social issues. Twenty-five percent of patients thought that pregnant women with epilepsy should discontinue their AEDs. Two of the lowest scores, 13.6 and 47.5%, pertained to certain questions on the legalities of driving and employment, respectively.

DISCUSSION

Our findings are similar to studies of different patient populations. A lack of patient knowledge of their condition has been reported in patients with congestive heart failure (9), gastroesophageal reflux disease (10), tuberculosis (11), and arthritis (12). In our study, epilepsy patients referred to a tertiary care center demonstrated limited knowledge of their disorder. This was true regardless of educational background, number of years with epilepsy, or age. One would expect older, educated patients with a long history of epilepsy to be more knowledgeable about their disorder. Our study did not support this assumption. Although characteristics varied, our patients were similar in that they were all referred to a tertiary care center. This limits the ability to generalize findings to different epilepsy patient populations.

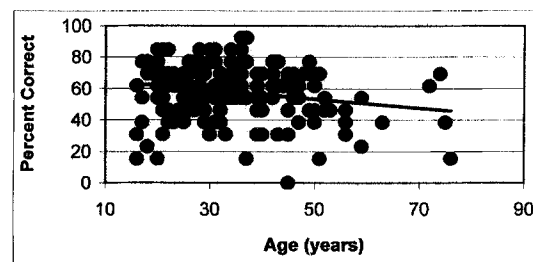


FIG. 1. Age correlation with questionnaire score. ($r = 0.20$, $p < 0.01$).

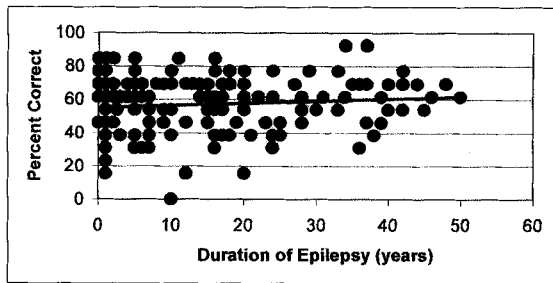


FIG. 2. Years with epilepsy correlated with knowledge scores. ($r = 0.09$, $p = 0.2$).

The lack of knowledge of epilepsy among patients with the disorder is consistent with previous studies. Although epilepsy patients in the study of Dawkins et al. (5) were more likely to know the different forms of epilepsy, epilepsy etiology, and information regarding seizure precipitates, overall people with epilepsy knew little more about their disorder than age-matched controls. In the Dawkins et al. study, 22% of patients in the control group thought that placing an object in a patient's mouth during a seizure is necessary to prevent tongue swallowing. In our study, 41% of patients with epilepsy believed this practice is appropriate. Whereas the Dawkins et al. study is limited because of a small sample size (epilepsy group, $n = 29$; control group, $n = 32$), and included epilepsy patients in general practice, both studies clearly indicate the need for educational interventions related to safety, as placing an object in a patient's mouth during a seizure not only predisposes the patient to oral mucosa damage, but also may occlude the patient's airway. Another safety issue that requires consideration relates to administering AEDs during pregnancy. Twenty-five percent of patients thought that pregnant women with epilepsy should discontinue their AEDs to prevent teratogenic side effects. This supports the need to emphasize the importance of compliance, particularly to epilepsy women of childbearing age.

A study in India evaluated the knowledge, attitudes, and practice of epilepsy at a rural health service center (13). About 25% of patients had no understanding of the etiology of epilepsy, and 9% thought it is caused by evil spirits. More than half of these patients tried alternative treatments, mainly indigenous medicines and spiritual interventions. A Nigerian study documented similar findings (14). In our study, 29.9% believed that epilepsy is contagious or a mental disorder. In a Tanzanian study, 40.6% of patients believed that epilepsy was infectious (15). Although there are cultural differences between our patients and patients in other studies, all findings support a lack of understanding of the etiology of epilepsy.

Although the question concerning driving laws may have been misleading, the majority of patients (86.4%) were not aware that the state of Ohio has no mandated

seizure-free interval before a patient can drive. Ohio law delegates this decision to the patient's physician. Approximately 25% of patients in our study believed it is appropriate to operate a motor vehicle if they either "double-up on medication," are not driving alone, or are able to "pull over" at the onset of a seizure. Although some patients with prolonged auras are given approval to drive, operating a motor vehicle after increasing AEDs and driving while accompanied are unsafe practices for patients with uncontrolled seizures. This finding not only supports the need to educate patients on driving restrictions, but also may imply a need for mandating state-regulated seizure-free intervals before driving.

In terms of employment, 84.8% of patients believed that people with epilepsy can work in many types of jobs. Although the decision to disclose the diagnosis of epilepsy remains controversial, 52.5% of patients did not know that is illegal for potential employers to inquire about the diagnosis of epilepsy. Although data on patients' employment status were not collected, there is certainly an increased potential for discrimination if an informed employer is reluctant to hire a patient with this diagnosis. In this study, patients were more knowledgeable about questions related to compliance compared with other issues. Although this is true, data assessing whether or not patients actually administered medication as directed were not collected.

Although the knowledge questionnaire was not formally tested for validity and reliability, it provided useful information concerning the knowledge of epilepsy patients referred to a tertiary care center. Patients with epilepsy make independent decisions about their disorder on a daily basis. Health care professions have emphasized the need for improved educational interventions (7), but patients perceive a need for more information as well (14-16).

In one study patients preferred being educated by physicians (2), but nurses and other health care professionals must collaboratively promote patient education as a means to enhance therapeutic outcomes. Educational interventions may reduce the fear associated with seizures

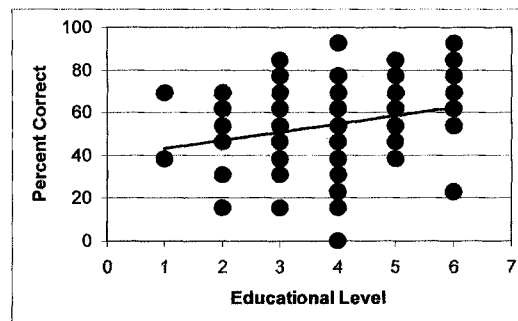


FIG. 3. Education level correlated with knowledge scores. Dots may represent more than one subject ($r = 0.34$, $p < 0.01$).

APPENDIX 1. *Epilepsy Patient Knowledge Questionnaire*

Please circle one answer for each question.

1. What is epilepsy?	70.1%
A. A mental disorder	
B. A disorder caused by abnormal electrical discharges in the brain	
C. A disorder that you can catch that causes people to shake all over	
D. Both A & B are correct	
E. None of the above	
SAFETY	
2. In epilepsy patients, which of the following situations will increase seizures?	65%
A. Not taking your seizure medication	
B. Not getting enough sleep	
C. Stress	
D. Alcohol withdrawal	
E. All of the above	
F. None of the above	
3. What two things can you do to reduce your chances of having a seizure?	52.5%
4. True or False To stop me from swallowing my tongue, an object should be placed in my mouth during a seizure.	59%
5. True or False To prevent birth defects, women with epilepsy should stop taking their medicine if they become pregnant.	75.1%
6. People with seizures may do all of the following activities: (Circle all that apply)	31.6%
A. Supervised swimming with trained personnel	
B. Exercise	
C. Drink one or two cans of beer or wine with dinner	
D. None of the above	
E. All of the above	
COMPLIANCE	
7. Please write out the name, dose, and frequency of your seizure medications.	84.7%
8. If you have side effects from your seizure medication, you can	77.4%
A. Immediately stop taking your medication	
B. Stop taking your medicine before talking with your nurse or doctor and wait to discuss side effects at your next appointment	
C. Call the emergency room and talk to a nurse or doctor about your side effects	
D. Contact your nurse or doctor and follow their directions concerning your medicine	
E. Put up with them	
9. If you stop having seizures while taking your seizure medicine, you can do the following:	92.1%
A. Stop your medicine because you do not need it	
B. Reduce your medicine without asking your nurse or doctor	
C. Continue taking medicine as ordered	
D. Stop taking your medicine every day and take double doses when you "feel a seizure coming on"	
LEGALITIES OF DRIVING AND EMPLOYMENT	
10. How long do you have to be seizure free to drive in the state of Ohio?	13.6%
11. If you are still having seizures, you can drive a car under the following conditions:	76.3%
A. If you drive only when someone else is in the car	
B. If you "double up" on your medication just before driving	
C. If you pull over when you feel a seizure coming on	
D. None of the above	
Answer the following questions by circling true or false	
12. True or False People with epilepsy can work in many types of jobs	84.8%
13. True or False When you apply for a job, it is illegal for employer to ask if you have epilepsy	47.5%

and reduce potentially harmful self-management practices. Future studies should focus on a larger sample size, more diverse population, and correlating knowledge scores with quality of life, seizure frequency, and seizure severity. Documenting a direct correlation between seizure status may provide an incentive for epilepsy patients to become more knowledgeable about their condition. As demonstrated in studies on other chronic conditions (17), improving patient knowledge may improve symptom control.

Acknowledgments: We acknowledge Dr. Sandy Cornett for her assistance with developing the Knowledge Questionnaire and Hoechst Marion Roussel, Inc., for their generous financial support.

REFERENCES

- DiIorio C, Henry M. Self-management in persons with epilepsy. *J Neurosci Nurs* 1995;27:338-43.
- DiIorio C, Manteuffel B. Preferences concerning epilepsy education: opinions of nurses, physicians, and persons with epilepsy. *J Neurosci Nurs* 1995;27:29-34.
- DiIorio C, Faherty B, Manteuffel B. Learning needs of persons with epilepsy: a comparison of perceptions of persons with epilepsy, nurses and physicians. *Am Assoc Neurosci Nurses* 1993;25:22-9.
- Hausman SV, Luckstein RR, Zwygart AM, Cicora KM, Schroeder VM, Weinhold OM. Epilepsy education: a nursing perspective. *Mayo Clin Proc* 1996;71:1114-7.
- Dawkins JL, Crawford PM, Stammers TG. Epilepsy: a general practice study of knowledge and attitudes among sufferers and non-sufferers. *Br J Gen Pract* 1993;43:453-7.

6. Tedman S, Thornton E, Baker G. Development of a scale to measure core beliefs and perceived self-efficacy in adults with epilepsy. *Seizure* 1995;22:1-31.
7. Ridsdale L, Robins D, Fitzgerald A, Jeffery S, McGee L, Epilepsy Care Evaluation Group. Epilepsy monitoring and advice recorded: general practitioners' views, current practices and patients' preferences. *Br J Gen Pract* 1996;46:11-4.
8. Goldstein LH, Minchin L, Stubbs P, Fenwick PB. Are what people know about their epilepsy and what they want from an epilepsy service related? *Seizure* 1997;6:435-42.
9. Hanya Ni, Nauman D, Burgers D, Wise K, Crispell K, Hershgerger RE. Factors influencing knowledge of and adherence to self-care among patients with heart failure. *Arch Intern Med* 1999;159:1613-9.
10. Jasani K, Piterman L, McCall L. Gastroesophageal reflux and quality of life: patients knowledge, attitudes and perceptions. *Aust Family Physician* 1999;28(suppl 1):S15-8.
11. Liam CK, Lim KH, Wong CM, Tang BG. Attitudes and knowledge of newly diagnosed tuberculosis patients regarding the disease, and factors affecting treatment compliance. *Int J Tuberc Lung Dis* 1999;3:300-9.
12. Lubrano E, Helliwell P, Parsons W, Emery P, Veale D. Patient education in psoriatic arthritis: a cross sectional study on knowledge by a validated self-administered questionnaire. *J Rheumatol* 1998;25:1560-5.
13. Desai P, Padma MV, Jain S, Maheshwari MC. Knowledge, attitudes and practice of epilepsy: experience at a comprehensive rural health services project. *Seizure* 1998;7:133-8.
14. Danesi MA. Patient perspectives on epilepsy in a developing country. *Epilepsia* 1984;25:184-90.
15. Rwiza HT, Matuja WB, Kilonzo GP, Mbena P, Mwang'ombola R, Jilek-Aall L. Knowledge, attitude and practice toward epilepsy among rural Tanzanian residents. *Epilepsia* 1993;34:1017-23.
16. Buck D, Jacoby A, Baker GA, Graham-Jones S, Chadwick DW. Patients' experiences of and satisfaction with care for their epilepsy. *Epilepsia* 1996;37:841-9.
17. Fernando DJ. Knowledge about diabetes and metabolic control in diabetic patients. *Ceylon Med J* 1993;38:18-21.