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Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy

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Abstract

Objective—Zambia suffers from a physician shortage, leaving the provision of care for those with epilepsy to nonphysician health care workers who may not be adequately trained for this task. These individuals are also important community opinion leaders. Our goal in this study was to determine the knowledge, attitudes, beliefs, and practices of these health care workers with respect to epilepsy.

Methods—Health care workers in urban and rural districts of Zambia completed a self-administered, 48-item questionnaire containing items addressing demographics, personal experience with epilepsy, social tolerance, willingness to provide care, epilepsy care knowledge, and estimates of others' attitudes. Analyses were conducted to assess characteristics associated with more epilepsy care knowledge and social tolerance.

Results—The response rate was 92% ($n = 276$). Those who had received both didactic and bedside training ($P = 0.02$) and more recent graduates ($P = 0.007$) had greater knowledge. Greater knowledge was associated with more social tolerance ($P = 0.005$), but having a family member with epilepsy was not ($P = 0.61$). Health care workers were generally willing to provide care to this patient population, but ~25% would not allow their child to marry someone with epilepsy and 20% thought people with epilepsy should not marry or hold employment. Respondents reported that people with epilepsy are feared and/or rejected by both their families (75%) and their community (88.8%).

Conclusions—Knowledge gaps exist particularly in acute management and recognition of partial epilepsy. More recent graduates were more knowledgeable, suggesting that curriculum changes instituted in 2000 may be improving care. Health care workers expressed both personal and professional reservations about people with epilepsy marrying. In addition to improving diagnosis

and treatment skills, educational programs must address underlying attitudes that may worsen existing stigmatizing trends.

Keywords

Stigma; Quality of care; Person with epilepsy; Tolerance; Knowledge

1. Introduction

Decreasing the global burden of epilepsy and bringing this condition “out of the shadows” require narrowing the treatment gap [1] and reducing epilepsy-associated stigma [1–3]. In sub-Saharan Africa, where the physician shortage is ever more dire [4], nurses and clinical officers must manage most cases of epilepsy. Zambia has only 0.7 physicians for every 10,000 people. In contrast, there are 12 nonphysician health care workers per 10,000 people [5]. Whether neurologic training for these professionals is sufficient for adequate epilepsy care provision without physician consultation is unclear. Clinical officers receive 3 years of clinical training after secondary school with a focus on managing the most common medical problems encountered in the region (e.g., malaria, gastroenteritis). Nurses in Zambia are trained for supportive care roles and, technically, are not supposed to prescribe medications or treatments, but clinics are often staffed only by nurses who inevitably dispense medications. Data from rural regions of Zambia indicate that many nurses and clinical officers working in primary care clinics have no physician on site, and their patient population lacks the resources to access physician-level care [6,7].

In addition to their professional role, health care workers represent one of the more highly educated and influential groups within African societies. Prior knowledge, attitudes, beliefs, and practice surveys conducted in Africa have been directed at the general public, students, or teachers [8–17]. Undoubtedly, health care workers’ perspectives of people with epilepsy impact their professional interactions with this patient population. Furthermore, their social response to people with epilepsy, independent of their provision of medical care, may influence others. In addition to their important role in care provision, nurses and clinical officers may be important social entities in determining how the community views people with epilepsy. Health care workers may also be able to provide us with insights into how people with epilepsy are viewed by their families and their communities.

We conducted a survey of Zambian health care workers to assess their epilepsy care knowledge, as well as their social attitudes, beliefs, and practices with respect to people with epilepsy, with some comparisons to other important social entities previously surveyed.

2. Methods

2.1. Study population

All clinical officers and nurses employed in or training at registered health care facilities in the Lusaka and Monze districts were eligible to participate in the study. Lusaka District encompasses health centers in the capital and the surrounding urban region. Monze, located in the Southern Province, serves a rural population. Health care workers were invited to participate during working hours. Those willing to complete the questionnaires did so outside of regular working hours and returned the surveys anonymously to a research assistant. Respondents were paid ZMK 20,000 (~\$US 4.00) for their transportation and participation. This study was reviewed and approved by the University of Zambia’s Research Ethics Committee as well as Michigan State’s University Committee for Research Involving Human Subjects.

2.2. Instrument

After reviewing several knowledge, attitudes, beliefs and practices instruments used by other groups studying epilepsy [11,18–23], we developed a 48-item questionnaire that elicited information on demographics (6 items), personal experience with epilepsy (3 items), social tolerance (4 items), epilepsy care knowledge (25 items, including five clinical vignettes), self-assessment of epilepsy care expertise (5 items), willingness to care for epilepsy (1 item), type of epilepsy care education received in the past (1 item), and perspective of how people with epilepsy/epilepsy are viewed by others (3 items). To assess willingness to provide epilepsy care, respondents were asked to indicate, on a scale ranging from 1 to 3, “how you feel about providing care for patients” with epilepsy as well as eight other common conditions. The survey was piloted among health care workers in adjacent health districts to develop the final survey instrument (see Appendix A). English is the official language in Zambia, the language of education, and was the only language in which this survey was conducted.

2.3. Analysis

Data were double-entered into Microsoft Access for accuracy before importation into EPI INFO Version 3.2.2 for analysis. In addition to descriptive details of the survey results, composite scores were calculated for social tolerance and epilepsy care knowledge. Among the items assessing personal experience with epilepsy, only the item “Do you have a close family member with epilepsy?” exhibited any variability, so no composite score was developed for personal experience. Epilepsy care knowledge scores were calculated on the basis of the proportion of correct answers on the 22 epilepsy care items that had distinctly correct/incorrect answers,¹ with a higher score reflecting more knowledge. Social tolerance scores were calculated on the basis of responses to four questions, with higher scores representing more tolerance. Epilepsy care knowledge and social tolerance were treated as continuous variables in our analyses. Willingness to provide care for various conditions was rank ordered. Student’s *t* test or the χ^2 test was used to assess how demographic characteristics, type of epilepsy care education received, and health care workers’ self-assessment of epilepsy care expertise related to epilepsy care knowledge scores.

3. Results

Of 300 health care workers eligible and invited to participate, 276 completed and returned surveys for a response rate of 92%. Demographic details, personal experience with epilepsy, and social tolerance information are provided in Table 1. The average age of respondents was 34, most were female (77%), and just more than half resided in urban areas. More than 98% of respondents knew someone with epilepsy and had witnessed a seizure. A third reported having a close family member with epilepsy. More than 95% of health care workers reported a willingness to allow their own child to play with a child with epilepsy and indicated that children with epilepsy could attend school. Furthermore, 75% of respondents would allow their son or daughter to marry someone with epilepsy.

Tolerance scores ranged from 0 to 4 (mean 2.42, median 3.0, mode 3.0, SD 0.96). Knowledge scores ranged from 11 to 21 (mean 12.4, median 13.0, mode 13.0). Willingness to provide epilepsy care ranked fourth among the nine common conditions assessed. More than 95% of health care workers reported being willing to care for all of the conditions listed *except* mental illness, whereas more than 15% of respondents indicated that they preferred not to take care of patients with mental illness (Table 2).

¹For example, we had no group consensus on the “correct” answer for those activities people with epilepsy can undertake (question 38), although we felt it was important to ascertain what health care workers thought were acceptable activities for someone with epilepsy.

Responses to epilepsy care knowledge-based questions are provided in Table 3. Although most health care workers recognized that epilepsy is not a contagious condition, fewer than 40% characterized it as a brain disorder. Approximately 90% recognize epilepsy as a condition requiring chronic treatment, but health care workers' acute management recommendations were suboptimal and included recommendation that something hard be placed in the person's mouth (58.8%) and the person should be held down (38.6%). Clinical vignettes were designed to determine whether health care workers could distinguish provoked seizures from epilepsy and could diagnose epilepsy in someone without generalized seizures. Twenty percent of health care workers failed to recognize recurrent complex partial seizures as epilepsy, and a similar proportion classified recurrent fever-provoked seizures as epilepsy.

Recommendations for activity limitations are summarized in Table 4. Overall, health care workers appear appropriately concerned about activities such as cooking (which generally involves exposure to open flames), driving, and swimming, but 20% indicated that people with epilepsy should be limited in their capacity to marry or hold employment.

Characteristics associated with higher epilepsy care knowledge are listed in Table 5. Epilepsy care knowledge scores were significantly higher for health care workers who had received both theoretic and clinical demonstration as part of their epilepsy care education ($P = 0.02$) and those who had completed training more recently ($P = 0.007$). There was a trend toward clinical officers possessing higher knowledge scores than nurses ($P = 0.07$). Health care workers' reporting higher self-assessments of epilepsy care knowledge had higher knowledge scores ($P < 0.0001$). The volume of epilepsy patients diagnosed or treated by the respondents in the past 3 months was not associated with knowledge scores ($P = 0.61$).

In terms of characteristics associated with more social tolerance, health care workers who reported having a family member with epilepsy *did not* demonstrate more social tolerance of the condition (3.4 vs 3.5, $P = 0.61$).

With respect to how others view people with epilepsy, health care workers indicated that among their family members, people with epilepsy are usually feared (48.1%) or rejected (26.9%), with only 20% of health care workers reporting that people with epilepsy are accepted. Health care workers viewed the community as even less supportive of people with epilepsy, reporting that the community rejects or fears people with epilepsy 49.8 and 39.0%, respectively. Only 7% of health care workers feel that people with epilepsy are accepted by their community.

4. Discussion

Some limitations of this study deserve mention. First, there may have been a bias toward "socially acceptable" answers from health care workers, particularly in light of the ongoing active campaign by the Epilepsy Association of Zambia to bring epilepsy out of the shadows at the time this survey was conducted. However, significant negative attitudes toward people with epilepsy were still evident among health care workers despite these efforts. Our epilepsy care knowledge items used in the composite were, by necessity, multiple choice and required, for example, drug recognition rather than recall. And respondents were not required to provide specific treatment regimens or diagnoses in the case-based scenarios. However, epilepsy care knowledge scores demonstrated reasonable variability and correlated well with knowledge self-assessments. Our sample did not include physicians, who may differ from nonphysician health care workers with respect to medical expertise and social tolerance regarding epilepsy. However, because the vast majority of people with epilepsy in Zambia cannot access physician-level care, [7], this survey captures data on the health care service personnel most people with epilepsy are likely to encounter.

The response rate for our survey was exceptionally high, and the sampling frame (all district health clinic nurses and clinical officers in one urban region and one rural region) provides a representative sample of Zambian health care providers and gives some valuable insights into epilepsy care in this region. The prevalence of epilepsy in this region is high [24], and as expected, health care workers have significant professional and personal experience with the condition. Although more than half the health care workers in this survey appeared to categorize epilepsy as a form of mental illness, ~98% were willing to treat people with epilepsy compared with 84% who were willing to treat mental illness. Clearly, “mental illness” encompasses a number of diagnoses including depression, anxiety, and various schizophrenias. We did not attempt to delineate willingness to provide care across psychiatric conditions, but suspect some symptoms represent types of mental illness that health care workers are particularly uncomfortable treating (e.g., psychosis).

Health care workers are more socially tolerant of people with epilepsy relative to Zambian clerics, more than 50% of whom would not allow their son or daughter to marry someone with epilepsy [25]. Zambian health care workers are almost universally willing to provide care for people with epilepsy. Unfortunately, significant gaps in epilepsy care knowledge are evident in both the diagnosis and treatment realms, suggesting that unless people with epilepsy have easier access to physician-level services, nurses and clinical officers require more epilepsy care education than they are presently receiving. Basic workshop-based training programs aimed at improving provision of epilepsy care by nonphysician health care providers in Zimbabwe have proven successful, at least in the short term [26]. In 2000, educational curricula for clinical officers and nurses in Zambia were expanded and enhanced to include more topics in neurologic care. The findings of this study, that more recent graduates have higher epilepsy care knowledge, suggests curriculum changes are associated with improved knowledge in the long term and are encouraging. Educational programs containing both didactic and bedside (i.e., practical) training in epilepsy care are associated with better knowledge and should be incorporated into prequalification and continuing medical education programs for nonphysician health care providers in this region.

In addition to addressing diagnostic and treatment issues, education programs must also address lifestyle recommendations made by health care providers to people with epilepsy and their families. Further qualitative studies are needed to explore why ~20% of the nurses and clinical officers surveyed thought people with epilepsy should not marry or hold employment, as such negative beliefs about the capacity of people with epilepsy to live full and functional lives may worsen stigmatizing attitudes already held by the general public. Despite social marketing campaigns, from the perspective of health care workers, epilepsy in Zambia is still a condition that results in fear and rejection by both the family and the community.

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Appendix A

Knowledge, Attitudes, beliefs and practices survey—Health care workers’ version

1. Please provide the following information:

Age _____
 Sex ☐ Male ☐ Female
 Highest grade attained _____ Other training

2. Marital status (*please check one*)

☐ Never married
☐ Currently married (monogamous)
☐ Currently married (polygamous)
☐ Divorced/separated/widow/widower (not remarried)
☐ Currently married (previously divorced)
 Number of children _____

3. Residence ☐ City ☐ Rural

4. Please indicate your qualifications²:

☐ Nursing student
☐ CO in training
☐ ZRN
☐ ZEN
☐ COG
☐ COP
☐ Other _____

5. Year of graduation _____

6. Employment ☐ Public clinic ☐ Private clinic

7. Please check the boxes below indicating the languages you speak.

(If nothing is checked, give "0".)

	Fluent	Some	None
English			
Nyanja			
Bemba			
Tonga			
Lozi			
Other (_____)			

8. Have you ever heard or read about the disease called "epilepsy"?

☐ No
☐ Yes—If yes, please give the local names for this disease.

9. Have you ever known anyone with epilepsy?

- ☐ Yes
- ☐ No
- ☐ Not familiar with epilepsy

10. Have you ever witnessed a seizure?

- ☐ No
- ☐ Yes-If yes, please check all those things you observed
 - ☐ Loss of consciousness
 - ☐ Tongue biting
 - ☐ Stiffening
 - ☐ Loss of urine or stool
 - ☐ Confusion
 - ☐ Staring

11. Would you allow your child to play with a child who has epilepsy?

- ☐ Yes
- ☐ No
- ☐ Not familiar with epilepsy

12. "A child with epilepsy should never attend school."

- ☐ True
- ☐ False
- ☐ Sometimes true
- ☐ Not familiar with epilepsy

13. Would you allow your *son* to marry a person with epilepsy?

- ☐ Yes
- ☐ No
- ☐ Not familiar with epilepsy

14. Would you allow your *daughter* to marry a person with epilepsy?

- ☐ Yes
- ☐ No
- ☐ Not familiar with epilepsy

15. How much do you know about epilepsy?

- ☐ Nothing
- ☐ Little
- ☐ Some
- ☐ A great deal

16. What type of training have you received on epilepsy?

- ☐ Theory only (estimate the number of lectures ____)
- ☐ Clinical demonstrations only (estimate the number of patients seen ____)
- ☐ Theory + clinical demonstrations

17. "Every person who has a convulsion has epilepsy."

- ☐ True
- ☐ False

18. "People with epilepsy should always be treated."

- ☐ True
- ☐ False

19. How effective is the treatment for epilepsy?

- ☐ Very good
- ☐ Good
- ☐ Not helpful

20. Which of the following drugs is used in the treatment of epilepsy?

(Tick all that apply)

- ☐ Aspirin
- ☐ Carbamazepine/Tegretol
- ☐ Chlorpromazine
- ☐ Phenobarbital
- ☐ Methyldopa
- ☐ Aminophylline
- ☐ Phenytoin/Epineutin

21. List the kinds of epilepsy you know:

22. What do you believe are the major *causes of epilepsy* in Zambia? Name all that you can.

23. What do you believe are the major *causes of seizures* in Zambia? Name all that you can.

24. Is it possible for some types of epilepsy to run in families?

- ☐ Definitely yes
- ☐ Possible
- ☐ Definitely not possible

25. Is epilepsy a contagious or infectious disease?

- ☐ Definitely yes

- ☐ Possible
- ☐ Definitely not possible

26. Can epilepsy be caused by head injury?

- ☐ Definitely yes
- ☐ Possible
- ☐ Definitely not possible

27. Can epilepsy be caused by birth asphyxia?

- ☐ Definitely yes
- ☐ Possible
- ☐ Definitely not possible

28. Is epilepsy always a brain disorder?

- ☐ Definitely yes
- ☐ Possible
- ☐ Definitely not possible

29. Can chronic alcohol drinking lead to epilepsy?

- ☐ Definitely yes
- ☐ Possible
- ☐ Definitely not possible

30. Do you think epilepsy can be treated?

- ☐ Always
- ☐ Sometimes
- ☐ Never

31. Generally, what is the attitude of the family toward the patient with epilepsy?

- ☐ Accepting
- ☐ Fearful
- ☐ Rejecting
- ☐ Don't know

32. What is the length of time people with epilepsy have the disease?

- ☐ Days
- ☐ Weeks
- ☐ Months
- ☐ Years

33. "Epilepsy is a mental illness".

- ☐ True
☐ False

34. What is the attitude of the community toward patients with epilepsy?

- ☐ Accepting
☐ Fearful
☐ Rejecting
☐ Don't know

35. Health care workers take care of patients with many different medical conditions. Please indicate below *how you feel about providing care* for patients with various disorders using the following scale:

- a.** I do not mind caring for these patients
b. I prefer not to care for these patients
c. I refuse to care for these patients

	1	2	3
Tuberculosis			
Malaria			
Gastroenteritis			
Epilepsy			
Hypertension			
AIDS			
Mental illness			
Pneumonia			
Diabetes			

36. Do you believe that epilepsy is a major health problem in Zambia?

- ☐ Definitely yes
☐ Possible
☐ Definitely not possible

37. Please indicate in the table below who may have epilepsy in Zambia.

Age group	Common	Sometimes	Never
0–5 years			
6–14 years			
15–25 years			
26–45 years			
46–65 years			

Age group	Common	Sometimes	Never
65+years			

38. What *activities* can a person with epilepsy participate in?

	Definitely yes	Possible	Definitely not
Get married			
Breastfeed			
Take part in dancing			
Participate in sports			
Take beer or other alcohol			
Have a job			
Swim			
Travel alone			
Go to healer			
Drive			
Cook			
Work with machines			
Attend school			
Climb trees			

39. How much experience do you feel you have had in the care of people with epilepsy?

- ☐ A great deal
☐ Some
☐ Few
☐ None

40. How many cases of epilepsy have you *diagnosed* in the past 3 months?

41. How many cases of epilepsy have you *treated* in the past 3 months?

42. What would you do for a patient who is having a tonic-clonic seizure?

(Tick all that apply)

- ☐ Turn the patient on their side
☐ Give oxygen
☐ Place a hard object in the mouth
☐ Keep your distance
☐ Hold them down

For the following cases, please indicate if the patient has epilepsy or not.

43. Case 1: A 2-year-old child with +MPs and a temperature of 40 °C has a generalized tonic-clonic seizure. The child has never had a seizure before.

- ☐ Epilepsy
- ☐ Not epilepsy
- ☐ Maybe epilepsy
- ☐ Don't know

44. Case 2: A 2-year-old child with +MPs and a temperature of 40 °C has a generalized tonic-clonic seizure. The child had a seizure last year, also during a high fever.

- ☐ Epilepsy
- ☐ Not epilepsy
- ☐ Don't know

45. Case 3: A diabetic accidentally takes too much insulin and the glucose drops very low. While the blood glucose is low, the patient has a seizure.

- ☐ Epilepsy
- ☐ Not epilepsy
- ☐ Don't know

46. Case 4: A 14-year-old is brought from school after a generalized tonic-clinic seizure. The child now looks fine (an hour after the seizure). You are told this has happened before on at least two occasions.

- ☐ Epilepsy
- ☐ Not epilepsy
- ☐ Don't know

47. Case 5: A patient is brought to you with episodes of confusion that begin with staring and sometimes involve strange movements of the mouth. The patient has never completely lost consciousness or fallen.

- ☐ Epilepsy
- ☐ Not epilepsy
- ☐ Don't know

48. Do you have a close family member with epilepsy?

- ☐ Yes
- ☐ No
- ☐ Not familiar with epilepsy

Thank you for participating in this survey. We welcome any comments you have regarding this survey. Please place them below.

A.1. Comment

²Co, clinical officer; ZRN, registered nurse; ZEN, enrolled nurse; COG, general clinical officer; COP, psychiatric clinical officer.

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Table 1Demographic data, personal experience with epilepsy, and social tolerance for epilepsy ($n = 275$)

Demographic data	
Age	
Mean	34.3
Median	34.0
Mode	28.0
Range	19–62
Clinical officers ^a	22.9%
Male	23.0%
Years of formal education	
Mean	12.3
Median	13
Mode	13
Range	9–13
Marital status (married)	50.0%
Number of children	
Mean	2.5
Median	2
Mode	0
Range	0–11
Urban residence	58.5%
Fluent in English ^b	98.1%
Personal experience with epilepsy	
Has heard of epilepsy	100%
Knows someone with epilepsy	98.2%
Has witnessed a seizure	98.2%
Has a family member with epilepsy	33.2%
Social tolerance	
Would allow their child to play with a child with epilepsy	97.1%
Would allow son to marry a person with epilepsy	74.8%
Would allow daughter to marry a person with epilepsy	73.3%
Believes a child with epilepsy should <i>never</i> attend school	3.6%

^aVersus nurse.^bFluent in English.

Table 2Willingness to provide care ($n = 275$)

Condition	Willingness score ranking (% unwilling to provide care ^a)
Malaria	1 (0.8)
Pneumonia	2 (1.5)
Hypertension	3 (1.9)
Epilepsy	4 (2.3)
Diabetes mellitis	5 (3.8)
Gastroenteritis	6 (3.8)
HIV/AIDS	7 (4.5)
Tuberculosis	8 (4.9)
Mental illness	9 (15.7)

^aThe higher the score, the less willingness to provide care.

Table 3Epilepsy care knowledge responses ($n = 276$)

Response	%
Epilepsy is due to:	
Contagious/infectious disease	5.6
Head injury	95.9
Birth injury	86.2
Brain disorder	62.3
Mental illness	54.8
Every person who has a convulsion has epilepsy (answered "yes")	2.9
Available treatments for epilepsy are "good" or "very good"	98.8
Epilepsy is a public health problem (answered "yes")	52.3
Epilepsy requires chronic treatment (answered "yes")	89.8
Correctly identified drug as AED ^a	
Aminophylline	100
ASA	96.4
Carbamazepine	81.5
Chlorpromazine	81.5
Phenobarbital	88.4
Phenytoin	79.3
Recommendations for what to do when someone has a seizure:	
Stand back, away from the patient	1.5
Put something hard in his or her mouth	58.8
Hold him or her down	38.6
Give oxygen	29.4
Turn person on his or her side	92.6
Vignettes	
Case 1: Knew that a malaria-induced seizure was not epilepsy	89.7
Case 2: Knew a febrile seizure was not epilepsy	79.6
Case 3: Knew a hypoglycemic seizure was not epilepsy	94.5
Case 4: Correctly diagnosed a patient with generalized tonic-clonic seizures	95.6
Case 5: Correctly diagnosed epilepsy in a patient with complex partial seizures	80.8

^aWe included only anticonvulsants commonly available in Zambia (phenobarbital, phenytoin, carbamazepine).

Table 4

Health care workers' recommendations on activities people with epilepsy can undertake

Activity	Yes (%)	No (%)	Possibly (%)
Attend school	88.4	0.7	10.8
Breastfeed	87.2	0.8	12.0
Be employed	81.1	0.4	18.6
Marry	80.3	0.4	19.3
Dance	62.9	6.4	37.1
Do sports	33.6	16.0	50.4
Cook	20.4	22.3	57.3
See healer	19.8	41.9	38.3
Travel	9.1	40.8	50.2
Drink alcohol	5.4	73.1	21.5
Drive	3.8	65.4	30.8
Work with machine	3.8	71.2	25
Climb trees	2.3	72.6	25.1
Swim	1.9	85.1	13.0

Table 5

Characteristics associated with higher epilepsy care knowledge

Characteristic	<i>P</i> value
Training (clinical officer 22.9% vs registered nurse 77.1%)	0.07
Type of instruction (clinical demonstration + theory 42.9% vs either alone 57.2%)	0.02
Fewer years since completing training (range 0–33, mean 9.8, median 8.0)	0.007
Residential status (urban 58.5% vs rural 41.5%)	0.40
Willingness to provide care score ^a	0.51
Has diagnosed case in past 3 months (55.9%)	0.58
Has treated case in past 3 months (90.2%)	0.47
Self-assessment of epilepsy knowledge (4-point Likert scale)	<0.0001

^a See Table 2.