

# Community Awareness of Which Seizure Type Should Present to Healthcare Providers: A Potential Risk Factor of Epilepsy Treatment

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## ABSTRACT

**Objective:** The objective of this study was to assess the Sudanese community's awareness about necessity of presentation of different seizure types.

**Methods:** This is a cross-sectional descriptive internet-based survey that was distributed to Sudanese participants via Google forms from January to April 2018. The survey consisted of demographic data (age, gender, educational level), a statement evaluating participants' sources of obtaining epilepsy-related knowledge, a statement assessing awareness about the appropriate primary care provider for People with Epilepsy (PWE), and a statement describing the symptomatology of different seizure types in simple Arabic, asking what description(s) participants thought should present to health care providers. We included participants residing in Sudan, and those with university or higher education. Four hundred sixty-seven participants completed the survey.

**Results:** 467 participants were included, of whom, 279 (60%) were females. The mean age of participants was 28 years. Two-thirds of participants obtained their information from non-scientific sources. 84% of the participants were aware that doctors are the primary health care providers for people with epilepsy. The majority (92%) of participants were aware that patients with symptoms corresponding to the generalized tonic-clonic seizure description should present to doctors, compared with two-thirds of participants for the description of focal seizure with retained awareness, and only 30.6% of participants for absence seizure symptom description.

**Conclusion:** This study demonstrated poor awareness about the necessity of presentation for absence and focal seizures with retained awareness. We hypothesize that this lack of awareness may contribute to epilepsy treatment gap, and we recommend further studies to examine this hypothesis.

**Keywords:** Knowledge; Perception; Types of epilepsy; Seizure description; Sudan

## INTRODUCTION

Epilepsy is the most common neurological disease that requires long-term healthcare, affecting almost 70 million patients [1], and 500 million family members and caregivers worldwide [2]. Epilepsy Treatment Gap (TG) is defined as the difference between the number of people with active epilepsy and the number of people whose seizures are being appropriately treated in a given population at a given point of time [3]. It is estimated to be 90% of People with Epilepsy (PWE) in the developing world [4-6]. Many factors are thought to contribute to this gap,

including factors related to health-care availability (manpower, medications, and cost of treatment) and factors related to misconceptions about the disease [7]. These misconceptions can lead to failure seeking appropriate healthcare, increasing cost of care, and may contribute to epilepsy stigma. Studies reported people traveling long distances and donating treasured items to healers in exchange of epilepsy treatments [4]. In a meta-analysis by Mbuba et al, the effect of misconceptions about epilepsy on TG had a variable magnitude (56%; CI: 31.1%-100%) [7], this variability was greater in studies from Africa (from Gambia, Tanzania, Senegal). Healthcare unavailability has a bigger impact

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on epilepsy TG than misconceptions about the disease [7]. Nevertheless, providing drugs was insufficient in reducing TG unless combined with educational campaigns [8,9]. Education also reduces the negative psychosocial effect of epilepsy, which helps improve patient's quality of life.

Seizures can have many forms, including convulsive seizures, staring episodes, and olfactory abnormalities. We hypothesize that different seizure presentations are perceived differently in terms of presentation to doctors, stigma, and the other psychosocial aspects. People who have a dramatic presentation (convulsive seizures) may be more prone to discrimination, while children with staring episodes may be perceived by their schoolteachers as careless. Although both conditions have a similar pathophysiology and management strategy, the first group tends to present to traditional treaters, while the second group tend to be ignored and remain without treatment. In this study, we investigate the awareness about the appropriate healthcare provider when treating epilepsy; a crucial factor measuring misconceptions about epilepsy. We investigate the awareness of the educated community in Sudan about the necessity of medical evaluation of different seizure types. This study can serve as a comparison point for future studies involving the general Sudanese population.

## METHODOLOGY

### Study design and setting

This cross-sectional descriptive study was conducted in Sudan during the period from January to April 2018 using an online survey that was distributed in social media groups containing diverse groups of Sudanese people. We used Google Forms to collect out data. It is an online data collection tool that allows automatic export of results into files compatible with various analysis software. The post included a brief description of the study purpose and a link to enter the survey webpage. The first page in the survey included a more comprehensive description of the study and a consent form. The following pages included the questionnaire with each question detailed in a separate subsection.

This method was utilized to increase the number of study participants. We did not collect any personal identifying information or email addresses and the participants were completely anonymous. In order to increase our confidence in the understandability of the questionnaire items, we distributed a pilot form to a representative sample of 20 participants. We then interviewed them in person and utilized their feedback to improve the final form of the questionnaire. When asked to give feedback about the understandability of the final questions, all the participants agreed that it was easy to understand.

### Participants

Our targeted population was the Sudanese people with university or higher education. We excluded participants who are less than 18 years of age and those who reside outside of Sudan. While the participant of this study represents only the educated section of the Sudanese community, the results of this

study could highlight the knowledge level of this community and serve as a comparison for future studies (Table 1).

Data	Number (N=467)
Gender	
Male	188 (40.3%)
Female	279 (59.7%)
Age	
Mean age	28.1 years
Standard deviation	8.435 years
Educational level	
University	357 (76.4%)
Higher education	110 (23.6%)
Source of information	
Scientific source (book, health care provider, education)	284 (60.9%)
Nonscientific source (social media, people in community)	289 (61.9%)
No source	49 (10.5%)

**Table 1:** Demographical data of our participants.

### Statistical methods

We collected data from 467 participants, and then analyzed the data using IBM SPSS statistics version 25 and used Pearson's Chi-square test, and t-test to test for possible associations between variables.

### Variables

The questionnaire consists of;

1. Age, Gender.
2. Statement evaluating participant's awareness of the appropriate care providers for people with epilepsy.
3. One question evaluating participants source(s) of obtaining information regarding epilepsy.
4. One question giving a description of a seizure symptomatology and asking whether a patient with this presentation should present to a doctor (seizure types included were: GME, focal seizures with retained awareness, and absence seizures).

## RESULTS

We included 467 participants in our study, with females representing 60% (279). The mean age of our participants was 28 years. Ages ranged between 18 and 73, and the distribution

curve was positively skewed. Two-thirds of participants obtained at least some information about epilepsy from non-scientific sources. Eighty four percent of the participants were aware that doctors are the primary health care providers for people with epilepsy. Most of our participants (92%) were aware that patients with the symptomatology of GTC seizures should present to a doctor, while only two-thirds in the case of myoclonic seizures and focal seizures with retained awareness (68.5% and 67% respectively). Only one third (30.6%) were aware that absence seizure symptomatology should present to a doctor (Table 2).

	Women	Men	Higher education	University education
Absence	149 (32%)	131 (28%)	159 (34%)	135 (29%)
Generalized tonic-clonic	439 (94%)	420 (90%)	430 (92%)	434 (93%)
Myoclonus	327 (70%)	303 (65%)	350 (75%)	303 (65%)
P<0.03				
Focal seizures with retained awareness	317 (68%)	294 (63%)	327 (70%)	299 (64%)

**Table 2:** Percentages of people who think that seizure descriptions should present to the doctor. The P-value for the chi-square test is provided for the significant association.

## DISCUSSION

This study demonstrated a difference in awareness about the appropriate healthcare provider to care for a patient with epilepsy. Most of our participants (92.7%) were aware that people with generalized tonic-clonic seizures need to present to doctors, while only 30.6% thought so in case of absence seizures and 67%, 68.5% in focal seizures with retained awareness and myoclonic seizures respectively (Table 3).

Participants knowledge	Number (N=467)
Participants knowledge about the primary care provider for people with epilepsy	
Doctors	392 (83.9%)
Other healers	75 (16.1%)
Participants' knowledge of which seizure description should present to a doctor*	
Generalized tonic-clonic epilepsy	433 (92.7%)
Focal seizures with retained awareness	313 (67%)

Myoclonic seizures	320 (68.5%)
Absence seizures	143 (30.6%)

**Note:** \*Seizure types displayed in the table represent the diagnoses associated with the symptomatologic descriptions that we provided our study participants in the questionnaire. The descriptions were written in simple Arabic language and can be found in the questionnaire (found in the appendix section).

**Table 3:** which seizure description should present to the doctor.

Possible explanations include a more dramatic presentation in generalized tonic-clonic seizures as well as perceived danger to health. Notably, absence seizures tended to be ignored. Although the condition usually resolves by adulthood, it affects aspects such as school performance, social wellbeing, and personality. It is especially amenable to treatment as more than 90% of patients become seizure free after treatment [9]. More than 80% of our participants thought that doctors are the primary care providers for people with epilepsy rather than other healers. We asked our participants which resources they used to obtain their knowledge about epilepsy. Participants were allowed to ask more than one answer (Table 4).

	Women	Men	Higher education	University education
During studies	(149) 32% P<0.00	(75) 16%	(103) 22%	(126) 27%
People in the community	(187) 40% P<0.00	(257) 55%	(210) 45%	(219) 47%
People in the medical field	(112) 24%	(98) 21%	(149) 32% P<0.01	(93) 20%
Social media	(33) 7%	(37) 8%	(37) 8%	(33) 7%
Journal/book	(56) 12%	(61) 13%	(84) 18% P<0.04	(51) 11%
No source	(33) 7%	(56) 12%	(23) 5% P<0.02	(51) 11%

**Table 4:** Sources of knowledge chosen by participants. P values for the chi-square test are provided for significant associations.

More than half of our participants reported at least one non-scientific source of knowledge about epilepsy. This can propagate misinformation and magnify existing stereotypes about epilepsy. We hypothesized that people regard epilepsy to present as convulsive seizures. Our findings are not conclusive but support our hypothesis. Our study sheds light on an important factor that can contribute to TG in Sudanese people with epilepsy.

## CONCLUSION

From the above results, we can understand that majority of the participants thought that doctors were primary care providers for epilepsy than other healers, and around 60% of participants

described non-scientific knowledge about epilepsy. Where it can lead to misinformation and rise in the existing stereotypes in public and many patients about epilepsy. This study demonstrated poor awareness about the necessity of presenting to a healthcare provider when experiencing symptomatology of absence and focal seizures with retained awareness. We hypothesize that this lack of awareness may contribute to the epilepsy treatment gap, and we recommend further studies to examine this hypothesis.

## LIMITATIONS

As people with higher educational levels are expected to have better awareness about epilepsy, the deficiencies that we found might be more pronounced in the general population. Including only highly educated people in our study prevented the analyzing the correlation between educational level and awareness about epilepsy.

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## AUTHOR'S CONTRIBUTIONS

Ismat Babiker co-formed the study concept and design, co-developed the questionnaire, distributed the data collection sheet, and co-wrote all sections of the final manuscript.

Mohamed K. Elnaeim co-formed the study concept and design, co-developed the questionnaire, distributed the data collection sheet, and co-wrote all sections of the final manuscript.

Awab K. Elnaeem co-formed the study concept and design, co-developed the questionnaire, analyzed the data using IBM SPSS Statistics, distributed the data collection sheet, and co-wrote all sections of the final manuscript.

## ETHICAL CONSIDERATIONS

The participants provided their written informed consent to participate in the study; the consent form was attached before the data collection sheet. There are no potentially identifiable human images or data is presented in the study.

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