

# Knowledge and attitudes toward epilepsy among the educated community in Sudan

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## Research Article

**Keywords:** awareness, seizure(s), population, Africa

**Posted Date:** October 21st, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-993005/v1>

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# Abstract

## Background

many challenges and social barriers facing people with epilepsy (PWE), are mainly due to lack of knowledge and negative attitudes of communities toward PWE. Despite advancement in the understanding of epilepsy and the availability of epilepsy treatment, the objective of this study was to assess knowledge and attitude toward epilepsy among the educated community in Sudan.

## Methods

in this cross-sectional descriptive internet-based survey that was conducted in Sudan during the period from January to April 2018, we developed a structured questionnaire that consists of demographic data and 16 statements to evaluate knowledge and attitude of the participants toward the nature of epilepsy, and social factors related to epilepsy. We used Google forms to collect data from participants who have a university degree or higher education.

## Results

four hundred sixty-seven participants were included of whom 279 (60%) were females, the mean age of participants was 28.1 years (S.D. +/- 8.435). The majority of participants obtained their information from non-scientific sources, 69.6% had witnessed a seizure attack, and 38.3% have a relative with epilepsy, 77.9% knew that epilepsy is a problem in brain cells, while only 27.4% were aware that genetic factors may contribute to epilepsy. The participants had good knowledge that epilepsy is an organic disease rather than possession by the devil (8.1%), or punishment from God (0.6%), they were also aware that epilepsy is neither a mental illness (82.9%), nor contagious (96.6%), they think that epilepsy is controllable (92.7%), but not curable (49.5%). Our studied group had positive attitudes regarding marriage and employment in people with epilepsy (PWE), allowing PWE to attend family gatherings (96.4%), permitting children with epilepsy (CWE) to go to school (94%), and their children to play with CWE (93.8%).

## Conclusion

the study demonstrated good knowledge and fair attitudes towards epilepsy. The female gender was significantly associated with good knowledge and positive attitudes towards epilepsy.

## Background

Epilepsy is a condition that has been historically stigmatized by communities(1). The word "epilepsy" itself derives from the Greek verb epi-lambanein, meaning to be 'seized', and the disease has long been

perceived to be 'otherworldly' or 'caused by sin or devil possession'(1). Although extreme acts of discrimination practiced in ancient times, such as spitting at people with epilepsy (PWE) and refusing to use the same dish as them(1) are not widely seen nowadays, the stigma of epilepsy caused by communities' knowledge of the disease is still an issue that adversely affects the quality of life of PWE.

In modern times, despite advancements in medicine, and a better understanding of the natural causes of epilepsy, as well as the availability of treatments for epilepsy, PWE faces many issues regarding their social life. These issues include education, employment, friendships, marriage, isolation from social events, as well as the stigma of being thought of as mentally ill, less intelligent than their peers, and of epilepsy itself as being contagious, untreatable, or caused by sin (2).

In this study, we aimed to highlight knowledge of some aspects of these issues in Sudan; an example of a community governed by tradition, where PWE are often treated by folk medicine.

As education is one of the major determining factors in knowledge toward epilepsy, we thought that focusing on the educated community separately would provide conclusions that are more meaningful.

## **Methods**

This cross-sectional descriptive study was conducted in Sudan during the period from January to April 2018. After reviewing the literature, we developed a questionnaire (see Tables 1 & 2) consisting of two sections: 1) Demographic data. 2) A section assessing knowledge and attitudes towards epilepsy, divided into One statement assessing the sources used to get information about epilepsy, Five statements assessing knowledge of the nature and causes of epilepsy, Eight statements assessing knowledge of social stigmas facing PWE. To assess these factors, we implemented a description of seizure types according to the International League Against Epilepsy (ILAE) classification. We described the clinical manifestations of each seizure type in simple Arabic language. In this paper, we will refer to these types using scientific terms.

We used Google Forms to collect data. Google form is a tool that allows data collection via a personalized survey. The information is collected and automatically connected to a spreadsheet from which it can be imported to analysis software programs. We distributed the questionnaire on the internet by posting it on large social media groups. The post included a brief description of the study and a request to complete the survey. We emphasized that the groups are not gender or occupation-specific. 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. We described the purpose and the uses of the survey in the consent included within Google forms.

## **Statistical Analysis**

We only included participants with a college education or higher education, and we included only people who resided in Sudan. We collected data from 467 participants, and then we analyzed the data using IBM

SPSS statistics version 25 and used Pearson's Chi-square test to test for possible associations between variables

## Results

Among our participants, 325 (69.6%) have seen a seizure attack, and 179 (38.3%) have a relative with epilepsy.

Women had better knowledge than men in most of the aspects, they knew of the possible controllability of epilepsy ( $P < 0.001$ ), that it is caused by a problem in brain cells ( $P < 0.001$ ), that it is not a mental illness ( $P = 0.007$ ), that children with epilepsy should go to school ( $P = 0.023$ ), and that doctors are the primary health care providers ( $P = 0.024$ ) for PWE. This may be partially explained by the fact that females tended to receive their information about epilepsy from education ( $P < 0.001$ ), while men from people in their community ( $P < 0.001$ ). Men were also more likely to cite no previous knowledge as an answer ( $P = 0.021$ ).

People who have a relative with epilepsy thought that epilepsy can be cured ( $P = 0.018$ ), that PWE can make friendships with others ( $P = 0.036$ ), and that doctors are the primary health care providers ( $P = 0.045$ ), but they tended to think that PWE is less intelligent than others ( $P = 0.027$ ) and that epilepsy is a punishment from God ( $P = 0.028$ ).

People who have a relative with epilepsy more often got their information from health care professionals ( $P < 0.001$ ), and people in the community ( $P = 0.022$ ).

## Discussion

Education is one of the main factors that influence communities' knowledge and attitudes toward epilepsy, making it important to conduct a study regarding this topic in this section of the population. Studies targeting specific populations are needed because they allow for indirect comparisons among them (6), and with the general population.

## Sources of knowledge about epilepsy:

Only a few of our participants cited sound scientific sources for their epilepsy-related knowledge, with 26% citing formal education, 11.6% citing a journal or a book, and 23.3% citing health care professionals, similar to what was reported from Nigeria(2).

The majority of participants acquired their knowledge from people in their community (45.8%), while 16.1% cited social media as their source of knowledge, and 10.5% cited no source.

This high prevalence of non-scientific sources is likely to contribute to and propagate false knowledge, and it is especially important to consider that almost half of the participants obtained their knowledge

from the community. This highlights the need for awareness programs at a community level, particularly in communities such as Sudan where many cultural and traditional prejudices against PWE are present.

## **Nature and causes of epilepsy:**

Among our participants, 8.1% cited possession by the devil as a cause, and 0.6% considered epilepsy to be a punishment from God. These percentages are less than those reported in the literature, as possession by the devil was cited as a cause in studies from Nigeria(2) (23%), Ethiopia(8) (20.3% of urban-residing participants and 34.6% of rural-residing participants), and two studies from Sudan, one including secondary school teachers(3) (21.5%) and one conducted targeting caregivers of children with epilepsy(4) (32.2%). Results from a study in Jamaica(9) show that this misconception is more common among people with secondary school educational levels or less (18.2%) compared to people with post-secondary school educational levels (8%).

It is interesting to note that out of the 8.1% of our respondents who thought that epilepsy is caused by devil possession, 68.4% of them also thought that it is caused by a problem in brain cells. This ties with the results from a study done in Sudan assessing doctors' knowledge and attitudes towards epilepsy(5), which showed that 10.3% of doctors think that epilepsy occurs due to possession by the devil. Even though doctors extensively understand the medical pathophysiology of the disease and this section of our studied group is likely to have some basic knowledge about the medical cause of epilepsy, this did not alleviate the misconception. This notion sheds light on the need for a deeper understanding of the source of this belief and the need for addressing the root of the belief rather than ignoring it and focusing on improving the knowledge of medical causes.

Only 3.4% of our participants thought that epilepsy is contagious, this is similar to studies from India(10) (4.7%), Turkey(11) (3.8%), Jamaica(9) (2.5%), and Silesia(12) (1%). It is different from studies done in Zimbabwe(13) (88%), Saudi Arabia(14) (21.2%), as well as the study done in Sudan targeting caregivers of CWE, where 50% of participants thought that it is contagious(4).

Seventeen percent of our participants considered epilepsy to be a mental illness, similar to reports from Silesia(12) (23%), Nigeria(2) (20.4%), Jamaica(9) (9% of post-secondary school participants and 24.8% of participants at secondary school level or less), Ethiopia(8) (18% of urban-residing participants and 17.1% of rural-residing participants), Saudi Arabia(15) (8.1%), and Turkey(11) (6.8%). These numbers are significantly less than those reported in studies from Saudi Arabia(14) (70%), India(10) (74.9%), Italy(7) (56.1%), and Kuwait(16) (50%)

## **Marriage and epilepsy:**

Questions used in the literature to assess the attitudes towards marriage vary, among others used a general statement approach that focuses on epilepsy being (or not) an impediment to marriage.

Questions that required personal consideration, either a marriage involving the participants or their children, were more negatively addressed, which tended to negatively skew the results(6). Of our

participants, 28.7% thought that it is harder for men with epilepsy to get a wife, in contrast to a higher percentage (38.1 %) of those who believed that it is harder for women with epilepsy to get a husband, this is similar to what was reported from Nigeria(2) (38.2%).

These negative attitudes are more than what is reported from Italy(7) (19.6%) and are less than what was reported from Konya(11) (61%), and Zimbabwe(13) (86%).

These differences between communities may be attributed to differences in cultural views about marriage.

Among our participants, 9.4% more respondents answered 'yes' when asked the question is it harder for women with epilepsy (WWE) (vs. men with epilepsy) to get a spouse, this did not differ based on the gender of the respondent.

This finding highlights the social and cultural stigma that particularly faces WWE, especially in cultures where women are faced with gender-based prejudices.

## **Employment and epilepsy:**

The majority of our participants (88%) stated that PWE should be allowed to go to work, similar to what was reported from Silesia(12) (75.3%), and different from what was reported from Nigeria(2), and Cameroon(17) (52.7%, 41.6% respectively).

## **Social factors and epilepsy:**

Ninety-four percent of our participants answered yes to the question Children with epilepsy should be allowed to go to school, this is similar to a study from Jamaica(9) (96%) and another from Zimbabwe(13) (82%).

Among our participants, 93.8% felt that is okay for children with epilepsy to play with others.

Other studies found in the literature asked whether or not participants would allow their children to play with a child with epilepsy, this more personal approach can generate more negatively skewed results than ours.

Our results are similar to those reported from UAE(18), Greece(19), Iran(20), Austria(21), Taiwan(22), and Konya(11) (93%, 86%, 82.5%, 82%, 82%, and 80.6% respectively). And are better than those reported from Saudi Arabia Riyadh(15), Kuwait(16), Saudi Arabia Aseer(14), Ethiopia(8), Cameroon(17), Jordan(23), Kuwait(16), China(24), and Nigeria(2) (73%, 72.4%, 60%, 57%, 57%, 43.7%, 43%, 27.7% respectively).

Most of our participants believed that PWE can make friendships (98%). This is similar to the results of a study from Silesia (12) (94.5%) and is more than results from Nigeria (2) and Riyadh (15) (79.6% and 54% respectively).

Only a few of our participants thought that PWE is less intelligent than their peers (7.7%), which is substantially lower than what was reported from the Kingdom of Bhutan(25), where two-thirds of health care workers and one-third of PWE shared this idea.

## **Limitations**

Due to the data collection method, the response rate could not be calculated, and the questionnaire used in this study has not been previously validated.

## **Conclusion**

Our participants showed good knowledge and a positive attitude toward epilepsy, except for their inadequate knowledge about the curability of epilepsy.

## **Declarations**

### **Competing interests**

The authors declare that they have no competing interests.

### **Authors' contributions**

All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

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

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

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

### **Acknowledgments**

We thank all of our participants for their involvement in the study.

We thank Dr. Awab Hashim for his assistance in preparation of the manuscript and figures of the article.

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## Tables 1-2

Tables 1-2 are available in the Supplementary Files section.

## Supplementary Files

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- [floatimage1.png](#)
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