Epilepsy stigma among medical students of university of Khartoum

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Research Article

Keywords: Epilepsy, Stigma, Medical students

Posted Date: July 13th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-708451/v1>

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Abstract

Background

Epilepsy is defined as having two or more unprovoked seizures, which result from excessive neuronal firing in the brain leading to sudden abnormal movements of the body. Epilepsy, which was known previously as the sacred disease, is still accompanied with stigma, myths, misconceptions that renewed with each age. Our main aim is to Assess epilepsy stigma among medical students, university of Khartoum.

Methodology :

A descriptive cross-sectional study was conducted on 331 medical students in University of Khartoum, between January to April 2021. Socio-demographic data of patients were recorded. Knowledge, behavior and reaction of participants towards patients during seizures were assessed.

Results

94% of participants heard about epilepsy. Only 24 respondents weren't familiar with epilepsy. Clinical students' knowledge was deeper than preclinical students. Belief in supernatural forces as a cause of epilepsy, magic spells and invasion by demons showed no statistically significant difference between clinical and preclinical students. Clinical students' behavior towards handling seizures correctly more than preclinical students. The majority of responses according relationships with people with epilepsy were positive.

Conclusion & Recommendations :

Medical students of University of Khartoum have good knowledge about epilepsy, as well as good attitude, behavior and relationships with people with epilepsy. More research is obviously required to better understand the roots of epilepsy stigma. Also more studies are needed to show stigma from patient perspective.

Background

Epilepsy, known previously as the sacred disease, affects more than 50 million persons worldwide, 10,000,000 of them are in Africa, which make epilepsy the most common chronic neurological disease(1) (2). Although humanity discovered epilepsy very early in history, 4000 years ago, it's still accompanied with stigma, myths, misconceptions and false stories that evolved with each age.

Epilepsy is defined as having two or more unprovoked seizures, which result from excessive neuronal firing in the brain leading to sudden abnormal movements of the body, uncontrolled muscular activity and sometimes maybe accompanied by losing of consciousness or abnormality in the senses (3). In Sudan, epilepsy remains as a stigmatized illness (2). The calculated prevalence of epilepsy in Sudan remains high as the community act towards people with epilepsy (PWE) negatively, which made most of them to keep their illness secretive or refuse the diagnosis (4).

Despite the fact that antiepileptic drugs (AED) side effects have a remarkable impact in PWE life but, the psycho-social burden forms the greatest impact in living overall. Whatever the age of a person with epilepsy (PWE) the disease lays its psychological problems in personal life. When accompanied with social stigma it complicates the situation more and coping with the disease becomes more difficult. Depression, anxiety, emotional distress, social isolation, poor communication skills, low self-esteem, learned helplessness, sense of loss of control of life and psychosis are all enlisted problems accompanying epilepsy. Moreover, low marriage and employment rate and decreased years of education make PWE at a higher risk for suicidal ideation and attempts. Not to mention that stigma affect patients' relationship with family and friends and make all these psychological problems worse. It is reported in Africa that some patients and their family don't go to doctors to avoid social discrimination which remarkably affects their seeking of health care and treatment ,so the patients' seizures remain uncontrolled and he can't lead a productive life free from seizures.

Although medical students are in close contact with different neurological diseases including epilepsy because of their career, although it is observed that some students, specially who are pre-clinical, still have some misconceptions about epilepsy. Many similar studies outside Sudan suggest that it is due to knowledge gap. Unfortunately there is shortage of studies that assess the knowledge of medical students and in Sudan public as general. Therefore this study hopefully is going to bring the light spot to this field and helps in determining the suitable educational method to bridge the Gap. Our aims are to Assess epilepsy stigma among medical students, university of Khartoum, to assess students' knowledge about epilepsy " definition, causes, misconception of its infectivity, treatment and management", to assess students' behavior and reaction towards person having a seizure and to assess students' relationship with a person with epilepsy (PWE).

Epilepsy has long been associated with stigma in many countries. "4,000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma." (5, 6). Epilepsy was once thought to be caused by malignant causes and associated with sin or demonic possession in ancient and primitive societies. Theories about epilepsy such as contagion and lunacy can be traced all the way back to antiquity. Even after biomedical explanations for epilepsy replaced the earlier magical ones, studies linking epilepsy to violent or criminal behavior, abnormal sexual activity, hereditary degeneracy, and a particular epileptic personality added to the stigma. These explanations have only served to reinforce negative stereotypes and stigmatize people(7). As an example, the Nankara ethnic group of Burkina Faso they are not buried, but are thrown into the mountains or into the holy bush when they die(1). Epilepsy is often misunderstood as a mental disorder or a contagious disease. Fear and confusion are common

reactions to involuntary behavior associated with some seizures, such as incontinence. Epilepsy-related discrimination can be found in all aspects of life, including healthcare and education, jobs, and social and family life(7).

Stigma, according to sociologist Erving Goffman, is a process in which other people's negative responses "serve to spoil one's own social identity." He claimed that stigmatized people are perceived as "not quite human" and thus "justifiable" targets for discrimination and prejudice(8, 9). Also he referred stigma to the loss of social status that results from having an attribute, such as a health condition, that has been culturally identified as undesirable and thus profoundly discrediting(7, 8).

Materials And Methods

Study design:

This was a descriptive, institution-based cross-sectional study.

Study area:

This study was conducted in University of Khartoum, Faculty of Medicine. There are 2335 medical students who are registered in the faculty. The curriculum is designed that the first three years is for the basic clinical sciences followed by three years of clinical sciences and practice. The neuroscience course is placed at the third year and medical students are exposed to the neurological illnesses through clinical rounds at hospitals in the remaining three years.

Study population :

Medical students at university of Khartoum Faculty of Medicine from all levels (1-6).

Inclusion criteria:

- 1)Medical student in University of Khartoum
- 2)Willing to participate in the study

Sample technique :

A systematic random sampling was conducted on undergraduate medical students at University of Khartoum, for a period of three weeks through online Google form. The questionnaire contained a total of 22 questions. The college has a total strength of 2335 undergraduate students. The purpose of the study was explained to each student, and those students who agreed to participate in the study were included. Participation was voluntary. 297 students were included in the study giving us a response rate of 90%. The study was carried out during the month of January 2021.

Sample size:

sample size is: 330

The sample size (n) is calculated according to the formula: $n = [z^2 * p * (1 - p) / e^2] / [1 + (z^2 * p * (1 - p) / (e^2 * N))]$

Where: $z = 1.96$ for a confidence level (α) of 95%, p = proportion (expressed as a decimal), N = population size, e = margin of error.

$$z = 1.96, p = 0.5, N = 2335, e = 0.05$$

$$n = [1.962 * 0.5 * (1 - 0.5) / 0.052] / [1 + (1.962 * 0.5 * (1 - 0.5) / (0.052 * 2335))]$$

$$n = 384.16 / 1.1645 = 329.886$$

$$\approx 330$$

The sample size (with finite population correction) is equal to 330

Explanation: Couldn't complete the sample size due to limitation of time , refusal to participate , unreached individuals.

Data collection :

The data was collected using online Google form using a self-administered survey.

Tools and measurements:

1. Demographics: The participants were asked to fill out demographic information, including gender, age, academic year , and residence .
2. Section to assess students' knowledge about epilepsy " definition , causes , misconception of its infectivity , treatment and management".
- 3.Students' behavior and reaction towards person having a seizure.
- 4.Students' relationship with an epileptic person.

Data analysis:

The data collected were entered into Microsoft excel database , and analyzed using SPSS v.26 system. Descriptive data: Mean, Median and frequencies. Inferential data: Pearson chi-square test Analysis for different sections was as follows, the study population was split into two groups , clinical students and preclinical. Then different variables underwent comparison between the two groups. The p value was checked for each variable to test the significance of the comparison.

Results

The age of participants was normally distributed. It ranges from 17 to 27 years old with median age 21(SD = **1.920**). The males participants were 86 (29%) and females were 211 (71%). Most of the participants reside at Khartoum city (44%). 278 (94%) of participants heard about epilepsy, While 19 (6.4%) didn't

heard. 12 (63,2%) of those didn't heard were preclinical students against 7 (36.8%) were clinical. The clinical participants in this study were 175(58.9%) against 122 (41.1%) at the preclinical level.

Pearson chi-square was done to compare between the two groups Knowledge and awareness about epilepsy causes and to explore misconceptions. All results were significant except for two options : magic spells and invasion by demons, surprisingly shows no significance.

Participants were asked about their source of knowledge about epilepsy. Most of the respondents chose the educational professional as their source of knowledge (n = 185). followed by Media " T.V, social media" (n = 161), a family member have epilepsy (n = 46), a friend with epilepsy (n = 34) in order. while 29 participants weren't familiar with epilepsy and no responses claimed that the participants had epilepsy themselves. Most of the participants chose education and profession as their source of knowledge and familiarity of epilepsy, but only 25 (13.6%) of the preclinical students chose this option. Most of those who weren't familiar with epilepsy were preclinical participants 22 (75.9%). Moreover, they comprise the majority of those who weren't sure about epilepsy definition [32 (82.1%)]. 173 participants believe that hospital admission is the best way for managing and treating epilepsy; 95 of them preclinical while 78 were clinical participants. Outpatient clinics was remarkably preferred by clinical participants (n = 95).

8 participants prefer taking the patient to a traditional healer; 6 of them were preclinical and only 2 were at clinical level. The test shows that the association was significant ($p < .001$). All test show significant association between the academic level and the behavior except for the choice " put something in his mouth ", which demonstrated no statistical significance ($p \text{ value} = .061$).

Most of the participants have not a problem in being a friend with PWE or working, employing, living with someone with epilepsy. However, half of the participants said they cannot marry a PWE. The participants who said they can marry a PWE were fewer at the preclinical level than those at the clinical level. Proportional differences between the students from different level were significant ($P = 0.025$).

Discussion

This study was held to estimate the weight of epilepsy stigma and misconceptions among medical students and to compare between the preclinical and clinical students' knowledge, behavior and relationships with PWE. The response rate was 90%. The preclinical students (41.1%), who haven't been exposed to the neuroscience course, represent the knowledge of the society and its cultural beliefs. The clinical students were (58.9%) from the total responses. Similar studies on medical students in Sudan were not previously conducted. Most of the literature was from a patient perspective. However, we found two studies targeting the same objectives, conducted on university students in Nigeria and Brazil.

It was found that 19 participants didn't hear about epilepsy; 7 of them were clinical, while 12 were preclinical, proportional difference was significant ($P = 0.043$). In comparison with a study conducted in University of Uyo, Faculty of Medicine in Akwa, Nigeria, only 2 participants out of 232 did not hear about epilepsy(2). One study in University of Campinas, UNICAMP, Brazil demonstrated that 61% of 1st year

medical students described their knowledge about epilepsy as insufficient in comparison to 11% of 3rd year students and 27% of 6th year students (5).

The aim of the study was to find out the origin of students' knowledge of epilepsy. In order, 185 (62.1 %) students chose educational career as their reason for learning about the disorder, followed by media (social media, TV, etc.) [161 (54 %)], a family member or relative with epilepsy [46 (15.4 %)], a friend 34 [(11.4 %)], and 29 students (9.7%) who said they were clueless of epilepsy. "You have epilepsy yourself" was not a choice selected by either of these participants. In Nigeria study 108 participants (46.75%) knew someone with epilepsy; 68 of them were clinical students, while 42 were preclinical students. It is assumed that the clinical students were more able to recognize their family or friend's diagnosis after the clinical exposure(2). In UNICAMP, Brazil, it was shown that the major source of information about epilepsy for the 1st year medical students was from physicians and books(5).

Sudanese cultural beliefs are framing epilepsy as from supernatural sources like demons invading the body or evil-eye or witchcraft. Dr. Tigani El Mahi (1911–1970), a well-known Sudanese intellectual, psychiatrist, and social scientist, recognized that beliefs are generally accepted in Sudan by both illiterates and educated people (10). This study explored those cultural beliefs among the students and it was found that 15(5%) participants chose the magic spell as a cause of epilepsy, while 18 (6%) chose demonic invasion. Surprisingly, those who chose these options were not significantly dissimilar (P value for previous options = .652 and .846 was not significant, respectively). However, those who hold these cultural beliefs are few in comparison with the total responses. Compared to the Nigeria study, fewer clinical students held those socio-cultural beliefs(2).

Infections as a cause of epilepsy was chosen by 91 participants (30.5%), but most of them were clinical students [74 (81.3%)], which indicate the probability that the clinical students in this study do not know the difference between the provoked seizures due to acute infections (e.g. acute meningitis) and epilepsy which is unprovoked seizures. It is also likely they have deep knowledge about symptomatic epilepsy which is caused by intracranial complications of chronic infections (e.g.neurocytotoxicosis). However, 286(92.3%) believe that epilepsy is not infectious. This favors the second probability, or the possibility that community health education to remove the misconception of epilepsy infectivity was effective. Anyhow, most of who believed in epilepsy infectivity were preclinical 8 (72.7 %) against 3 (27.3%) at clinical level (p value = .030 means the proportional difference was significant).Blood and Saliva were believed to be the main routes for transmission, noticing that clinical participant didn't choose any of other routes but saliva. Except for only one participant who chose feces was clinical student. In contrast, Nigeria study showed that more than a quarter of the participants believe that epilepsy to be transferable especially during the ictal period through saliva, blood, urine or feces, which make most of them not willing to help a person during seizure.

Nearly half of the participants weren't sure if a person with epilepsy can be fully cured (n = 145, 49%) most of them were preclinical, 88 (28.9%) think it can't resolve completely, while 66 (22.1%) believes it can be cured. In university of Uyo study, Nigeria, showed that most of the participants consider epilepsy a

treatable disease even though there was a statistical difference between the two groups with the clinical students more inclined to believe that epilepsy is a treatable disease.

Most of the clinical students think that outpatients clinic is the best place for treating epilepsy, while preclinical students preferred choosing hospital admission. Nevertheless some chose going to traditional healer ($n = 8$, 6 were preclinical against 2 of the clinical). In Nigeria study, some participants preferred traditional herbs and methods over antiepileptic drugs or hospital. This was an indicator that knowledge didn't wipe out the belief in traditional treatment(2).

Participants were asked about how they are going to act towards a person having a seizure? Amazingly no one of the clinical students chose to run away instead of helping. While only 9(3%) preclinical chose to run, maybe they think they would be harmed or they consider epilepsy as a contagious disease. The majority of participants in the Brazilian study were eager to assist, indicating that providing students with more knowledge about the different clinical symptoms would increase their confidence in dealing with people during seizures (5). In Nigeria study, 9 (7.44%) of the preclinical students and only one medical student chose to run away.

Clinical participants performed significantly better than preclinical participants in terms of knowing what to do and what not to do in the event of a seizure. The same result was shown in Nigeria study, concerning the correct measures to take when someone is having a seizure, the clinical students were better. They were more likely to help a person having a seizure by turning him to the side, protecting him from injury and loosening anything tight around his neck. These actions probe people's ability to touch people who are having seizures, as well as their concerns about doing so. Surprisingly, more of the basic students were more likely to assist the person to stand up after a seizure unlike the clinical students. More of the clinical students will reassure the person after a seizure(2). In the Brazilian study, the 1st, 3rd and 6th year medical students showed statistically similar choices according to the right procedures to take towards a person having a seizure, but the 3rd year participants were better. Restricting the movement and pulling the tongue out were chosen mainly by 1st year participants (5).

The study explored the participants' relationship with PWE, 54.5% of the participants will not marry a PWE, while the majority of the participants don't mind working or going to school or being a friend with someone with epilepsy. Also, they think PWE are normal people, but a minority had a problem in living or employing a PWE, although the majority took the positive choices. 41 participants (13.8%) were afraid from PWE. In Nigeria study, more than 70% stated they will not marry PWE. This is likely emergent from the misconception that epilepsy can be transmitted sexually. However, it was surprising that a quarter of the clinical participants don't mind marrying a PWE. Having a friendship with PWEs seemed more acceptable though the clinical students. Participants are therefore more likely to do things like live, trade, work, and hire a PWE. It was an indication that the majority of respondents had positive attitudes toward epileptics, such as empathy, compassion, and sympathy. (2). The same can be said for the Brazilian research, with even more impressive results when it comes to marriage and working for a PWE. However, it's possible that participants preferred to choose what was more socially appropriate, which may explain

the high number of students who would marry a PWE, but the same students believe PWE are more likely to acquire mental conditions and have offspring with malformations (5).

Conclusions

Medical students of University of Khartoum have a relative good knowledge about epilepsy, its causes and management. Only a few students have misconceptions about epilepsy, such as seizure infectivity, and believe in theories like supernatural forces that can induce epilepsy, such as demon invasion and witchcraft. The majority of students have good knowledge about handling seizures. Most of the students are capable of maintaining a normal relationship with someone who has epilepsy, such as marriage or friendship, also they may employ or work with them. However some had concerns about such a relationship. Clinical students have a more in-depth understanding of epilepsy and how to adequately manage a seizure than the students at preclinical level.

Recommendations

More researches are obviously required to better understand the roots of epilepsy stigma and how to lessen its impact. More researches on stigma from the perspective of patients are required.

Declarations

Availability of data and materials

The materials datasets used and/or analyzed during this study are available from the corresponding author on reasonable request.

Ethical Considerations

The research was conducted after approval by research committee in university of Khartoum, Faculty of medicine , Department of community medicine. Informed consent was obtained from all participants before participation in the study. Their participation was voluntary and withdrawal was allowed at any moment. High degree of confidentiality was preserved.

Competing interests

The authors declare that they have no competing interests.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authors' contributions

All authors participated in planning the study, data collection, results and discussion sections.

References

1. World Health Organization. Epilepsy in the WHO African Region: Bridging the Gap: The Global Campaign Against Epilepsy "Out of the Shadows." 2004;48.
2. Ekeh BC, Ekrikpo UE. The Knowledge, Attitude, and Perception towards Epilepsy amongst Medical Students in Uyo, Southern Nigeria. 2015;2015.
3. WHO. EPILEPSY : A manual for Medical and Clinical Officers in Africa and Clinical Officers. World Heal Organ. 2002;124p.
4. Mohamed IN, Elseed MA, Hamed AA, Abdel- ME, El-sadig SM, Omer IM, et al. Paediatrics and International Child Health Prevalence of epilepsy in 74, 949 school children in Khartoum State, Sudan. Paediatr Int Child Health [Internet]. 2017;9047:1–5. Available from: <http://dx.doi.org/10.1080/20469047.2016.1278110>
5. Caixeta J, Fernandes PT, Bell GS, Sander JW, Li LM. Epilepsy perception amongst university students: A survey. Arq Neuropsiquiatr. 2007;65(SUPPL. 1):43–8.
6. Kale R. The treatment gap. Epilepsia. 2002;43(SUPPL.6):31–3.
7. Jacoby A. Floor The Quadrangle, Brownlow Hill Liverpool, UK L69 3GB.
8. Bandstra NF, Camfield CS, Camfield PR. Stigma of epilepsy. Can J Neurol Sci. 2008;35(4):436–40.
9. Clair M. Matthew Clair, Harvard University Forthcoming in Core Concepts in Sociology (2018). Sch Harvard [Internet]. 2018; Available from: https://scholar.harvard.edu/files/matthewclair/files/stigma_finaldraft.pdf
10. Mohammed IN, Babikir HE. Original Article Traditional and spiritual medicine among Sudanese children with epilepsy. 2013;13(1):31–7.