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Public Stigma Associated with Epilepsy among Sudanese Residents in Alttondob Abu Kleioa Village, 2018-2019

Ethar Hajo Ahmed Elsheikh[1,*], Amna Muawia Eltayeb Ahmed[1], Omnia Salih Mahmoud Alawad[1], Eman Fathi Ahmed Mohammed[1], Ayman Sabir Abdalla Ibrahim[1], Eman Alfatih khalafallah Mohammed[1], Amiena Mohammed SidAhmed Mohammed[1], Ayat Abdelbagi Ahmed Mohamed[1], Ann Siralkhatim Hamad Ahmed[1], Ehab Mohemad Ezzaldeen Mahmoud[2], Ann Khidir Dawoud Mohammed[1], Amna Mahadi Mustafa Bakhit[1], Elawab Salah Musa Elbashir[1], Azhari Abdallah Mohammed Ali[1], Ahmed yahia Ahmed Hmd[1], Aya Mohamed Elgasim Mudawi[1], Ayah Abdelhamid Mohamed Elhassan Widatalla[1], Aya Elhag Adam Yousif[1], Ethar Abdullah Andullah Abdulmajid[1], Bdraddeen Eltayeb Karrar Babiker[1], Amna AwadElkarim AbdAlla Mohamed[1]

[1]5th year Medical students at University of Khartoum, Faculty of Medicine, Department of community medicine, Sudan

[2]Teaching assistant department of pharmacology Faculty of Medicine, University of Khartoum

[*]**Corresponding Author:** Ethar Hajo Ahmed Elsheikh, University of Khartoum, Faculty of Medicine, Department of community medicine, Sudan, E-mail: ethohajo97@gmail.com

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Abstract

Introduction: Epilepsy associated stigma in Africa has been described largely in terms of enacted stigma or discrimination. We conducted a study of 157 original inhabitants. Stigma is known as a sign of disgrace or collection of wrong thoughts towards something.

Objectives: The aim of this study is to study the social stigma associated with epilepsy in Alttondob Abukleioa village, Al-Jazeera state, Sudan.

Methods: A community-based cross-sectional descriptive study involving 157 original inhabitants is designed to examine the knowledge, attitude, practice, and stigma of epilepsy in Alttondob Abukleioa.

Results: A total of 157 participants were interviewed. The median age of respondents was 34 and were females (88.5%). Most (87%) of participants had a formal education. According to the impact of epilepsy, (64%) think that epileptic patients can't pose risk to others, and (53%) having a normal IQ. (53%) admitted they will not marry an epileptic patient, while (84%) of them are willing to participate with an epileptic patient in any social work, and (85%) said that they will admit their illness.

Conclusion: The findings indicated a need to increase epilepsy awareness programs as a means of increasing public knowledge of epilepsy with the aim of reducing stigma.

Keywords: Epilepsy; Social stigma

1. Introduction

1.1 Background

Seizures and epilepsy are not the same. According to The International League Against Epilepsy (ILAE) epilepsy is a disease of the brain defined by any of the following conditions: [1] Two or more unprovoked (or reflex) seizures that have more than one day between them; [2] one or more unprovoked (or reflex) seizure with 60% or more recurrence rate after two unprovoked seizures, occurring over the next 10 years; [3] diagnosis of an epilepsy syndrome.3 More than 50 million people worldwide live with epilepsy, and 80% live in economically backward and developing countries [1].

Myths and misconceptions in epilepsy are deeply rooted and resulted in considerable stigma and discrimination about the disease in society [2] Stigma is known as a sign of disgrace or collection of wrong thoughts towards something [3].

Hidden health problems such as epilepsy make the people with them at high risk of their societies stigmatization. The particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination [4].

Scambler's "hidden distress" model shows that after diagnosis an adult with epilepsy goes through felt stigma even before their condition is exposed in order to have enacted stigma. They will therefore try to conceal their condition and in the end cause more harm to themselves. And this is all dependent on the cultural and clinical aspects of a community (cited by WHO 2004).

As was once stated epilepsy was ignored and associated with stigma for nearly 4 hundreds years then followed by a century of knowledge but still associated with stigma [4].

Though the implications of epilepsy-related stigma for disease burden and quality of life are difficult to calculate, they are almost certainly of great significance in resource-poor countries. In these countries, epilepsy represents a major public health problem characterized by lack of prioritization and infrastructural support and a ‘‘treatment gap” [4].

Next to clinical interventions, interventions are also required that recognize epilepsy’s social course and the relevance and the importance of epilepsy-related stigma to overall disease burden and impact on the quality of life [4].

Discrimination against people with epilepsy in the workplace and with respect to access to education is also common [4].

Civil and human rights violations are more evident in resource-poor countries, especially where there has been a history of generalized rights abuse [4].

Absence of health insurance protection makes people with epilepsy at unfair risk. This discriminatory behavior translates into a restriction of the right to make adequate financial provision in guarding against risks to the individual and his or her family [3].

It has been reported that people with developmental disabilities, including epilepsy, experience a heightened risk of becoming victims of violence and abuse [4].

It becomes clear that although specific practices may vary from country to country, discriminatory attitudes and prejudicial behavior toward people with epilepsy are common across the globe [4].

The societies in Sudan are that of open housing especially in the rural areas, therefore, it is often difficult for epilepsy patients to conceal their condition especially if they have generalized recurrent seizures.

The aim of this study is to study the social stigma associated with epilepsy in Alttondob Abukleioa village, Al-Jazeera state, Sudan.

1.2 Problem statement and justification

50 million people around the world are affected by epilepsy and more than 85 % of them are living in a developing country [5].

Stigma towards people with epilepsy and other similar disabilities is culture based in many societies and this behavior does not change significantly for long time, which makes a heard psychological burden of the affected people.

Despite that epilepsy is not the only disease that results in a sudden loss of consciousness, people with epilepsy are the most affected regarding employability [6].

As few studies have addressed the stigma regarding epilepsy and fewer in Sudan this study has been undertaken to address the stigma regarding epilepsy and its effect on epilepsy patients and their families and to highlight the importance of increasing the awareness which will reduce the psychological burden of the disease [5].

2. Materials and Methods

2.1 Study design

A community-based cross-sectional descriptive study.

2.2 Study area

Elttondoub Abukilewa village belongs to Tamboul locality of Aljazeera State, Sudan.

2.3 Study population

Original inhabitants of Elttondoub Abukilewa village were above 18 years and were living in a household. Individuals with communication disabilities and those unwilling to participate were excluded from this study.

2.4 Sampling

To calculate the sample, size the following equation was used:

n=Z2*p (1-p)/d2

Where: n= minimum sample size required.

Z= standard error (with 95% confidence =1.96)

P= expected prevalence, which is (0.115) in Sub-Saharan Africa.

D= maximum accepted margin of error (5%= 0.05)

So, the sample size was 157.

Sampling technique: Convenient sampling. Due to a lack of information about the number of houses and the population size, convenient sampling was conducted. 20 trained data collectors were divided into 5 equal groups to cover a certain number of households in different directions, and an average of 4 responses was taken from each household.

2.5 Data collection

Technique: a structured face to face interview.

Tools: a questionnaire with close-ended questions designed by the Authors to cover the following variables: (1) Socio-demographical variables. (2) The impact of epilepsy stigma. Stigma Scale of Epilepsy (SSE) designed by Paula T. Fernandes [7] was used after taking permission to measure the third variable; which is the perception of the stigma. The SSE consists of 24 items with a maximum score =100, minimum score =0. Each item got 4 options; 1= not at all, 2= a little, 3= a lot, 4= totally.

2.6 Data analysis

Data was entered and analyzed using Statistical Package for the Social Sciences 20 (SPSS), and the results were presented by tables and percentages, SSE score and other continuous data were presented by mean median and standard deviation. P value of 0.05 was used as cutoff point of statistical significance for independent-sample t- test and one-way analysis of variance.

2.7 Ethical consideration

Ethical approval was taken from the department of the community medicine University of Khartoum. Verbal consent was taken from participants at the beginning of the interview. No information that can lead to the identification of specific subject was taken, codes were used instead of names to insure confidentiality.

3. Results

3.1 Social characteristics

A total of 157 participants were interviewed. The median age of respondents was 34 (rang = 18-90). The majority (88.5%) were females. Most (87%) of participants had a formal education with a minority (4%) had a job related to the medical field. All the participants were Muslims, the most (42%) reported Islamic sect was Sufi, with more than half (51%) said they are not belonging to a cretin Islamic sect. Only a minority (11%) claim not to hear about epilepsy (Table 1).

Gender		**Frequency**	**Percentage**
Male		18	11.5
female		139	88.5
Median age (std. dev.)		34 (14.7)	
Educational level:			
illiterate	Non formal education	16	10.7
Khalwa		3	2
Primary level	formal education	53	35.6
Secondary level		54	36.2
University/ postgraduate studies.		23	15.4
Job			
related to the medical field		6	3.8
Not related to the medical field		150	96.2
Religion			
Muslim not belonging to a cretin Islamic sect.		80	51.3
Muslim Salafi		11	7.1
Muslim Sufi		65	41.7
Did you ever hear about epilepsy?			
yes		140	89.2
no		17	10.8

Table 1: Social characteristics of the participants (n = 157).

3.2 The impact of epilepsy stigma

Although more than half of participants think that epileptic patients can't pose a risk to others (64%) and they are having a normal IQ (53%), most of participants (65%) admitted that they will not marry or let their children marry an epileptic patient. On the other hand most (76%) of participants said they will not divorce if their partner suffers from epilepsy after marriage. More than half (59%) were going to let their children play with an epileptic child, and most (84%) of them are willing themselves to participate with an epileptic patient in any social work and even have friendship with patients (68%). The majority (85%) of participants said that they will admit their illness if they have epilepsy (Table 2).

Do you think that the epileptic patient can poses a risk to others?	**Frequency**	**Percentage**
yes	42	**29.4**
no	91	**63.6**
i don't know	10	**7.0**
Do you think that the epileptic patients are having a normal IQ?		
yes	77	**53.1**
no	52	**35.9**
i don't know	16	**11.0**
Will you marry or allow your children to marry an epileptic patient?		
yes	41	**28.7**
no	93	**65.0**
i don't know	9	**6.3**
If your partner suffers from epilepsy after marriage, will you chose to divorce?		
yes	34	**23.4**
no	110	**75.9**
i don't know	1	**.7**
Will you allow your children to play with epileptic children?		
yes	85	**58.6**
no	59	**40.7**
i don't know	1	**.7**
Can you participate with an epileptic patient in any social work?		
yes	116	**84.1**
no	19	**13.8**
i don't know	3	**2.2**
Can you have a friendship with an epileptic patient?		
yes	96	**67.6**
no	44	**30.3**
i don't know	3	**2.1**
If you were an epileptic patient, will you admit your illness to others?		
yes	123	**84.8**
no	21	**14.5**
i don't know	1	**.7**

Table 2: The impact of epilepsy stigma on the participants' attitude toward the patients.

	Not at all (%)	**A little (%)**	**A lot (%)**	**Totally (%)**
Do you think that people with epilepsy feel able to control their own epilepsy?	64.8	12.4	6.9	**15.9**
What do (would) you feel when you see (if you saw) an epileptic seizure?				
Shock	35.0	16.8	18.9	**29.4**
fear	43.4	16.8	16.1	**23.8**
Sadness	7.7	14.0	37.8	**40.6**
pity	3.4	4.8	40.0	**51.7**
Which difficulties do you think people with epilepsy have in their daily lives?				
Relationships	25.2	28.7	25.2	**20.9**
Work	27.6	30.3	26.9	**15.2**
School	34.2	23.8	27.3	**14.7**
Friendship	49.1	21.2	17.7	**12.0**
Sexual	35.6	21.7	27.3	**15.4**
Emotional	34.0	18.1	31.9	**16.0**
Prejudice	42.4	17.4	22.9	**17.4**
How do you think people with epilepsy feel?				
Worried	21.0	14.0	32.2	**32.9**
Dependent	36.1	17.4	27.8	**18.8**
Incapable	34.7	16.0	31.3	**18.1**
Fearful	30.0	10.4	36.1	**22.9**
Ashamed	52.8	16.0	19.4	**11.8**
Depressed	23.6	16.0	40.3	**20.1**
No different	40.3	16.7	17.4	**25.7**
In your opinion, in which situation does prejudice against epilepsy occur?				
Social relationships	36.8	16.7	28.5	**18.1**
Marriage	31.7	17.9	27.6	**22.8**
Work	36.8	22.9	26.4	**13.9**
School	46.5	22.9	22.9	**7.6**
Family	75.7	9.0	11.1	**4.2**

Table 3: Stigma scale of epilepsy, participants' perceptions (n = 140).

3.3 Stigma scale of epilepsy

Mean of the stigma score was 43 (range = 6 -86). An independent- sample t test was conducted to evaluate the relationship between SSE and other variables (gender and education). Males had a higher stigma score (N = 14, SSE = 50) than females (N = 126, SSE = 42) but this difference was not statistically significant (t = 1.212, p = .24). Same for educational level in which there was a slight difference in SSE between participants with non- formal education (N = 17, SSE = 41), and those with formal education (N = 115, SSE = 43). The difference wasn’t statistically significant (t = -.302, p = .76). One way analysis of variance was conducted to evaluate the relation of SSE to the religion, the result indicates no statistically significant difference between the religious groups (p = .389) (Table 3).

4. Discussion

The aim of this study is to study the social stigma associated with epilepsy in alttondob abu kleioa village - Sudan
The questions were understandable for people to some sort except some perception's questions which needed more explanations and they took some time to think about the answers.

4.1 Regarding the impact of epilepsy stigma on the participants' attitude toward the patients

More than half of the participants think that epileptic patients can't pose a risk to others and they have a normal IQ, we think that is because most of the participants had a sort of formal education to know about the nature of the disease or because some of them may have some relatives with the disease.

Most of the participants admitted that they will not marry or let their children marry an epileptic patient, we think people in a rural area would not have enough education about epilepsy outcomes so they will not like to go through marriage with them. On the other hand, most of the participants said they will not divorce if their partner suffers from epilepsy after marriage, we think this is due to their Islamic culture and humble spirits.

More than half were going to let their children play with an epileptic child, this may be due to the education of some of them that epilepsy is not contagious. Most of them are willing themselves to participate with an epileptic patient in any social work and even have friendship with patients, maybe due to the same reason. Most of the participants said that if they were epileptic patients they would admit their illness to others, in a rural area with people near to each other, and Islamic culture that does not see the illness as something wrong from the patient or that make him shame, it is a normal response.

4.2 Regarding participants’ perceptions about epilepsy

Most of them think that people with epilepsy will not be able to control their own epilepsy at all because most have some sort of formal education and some have a job related to the medical field. Most of the participants said that they will not feel shocked or fear when they see (or if they saw) an epileptic seizure, we think because it is a common disease that occurs a lot nowadays, and the growing education helps people to understand that it is not a disease from the devil or any wrong beliefs.

Most of them said that they will feel sad and pity if the saw a patient with epileptic seizures, it is something normal in any human being- to be sad for his friend, neighbor or relative's suffering. Most of the participants think that people with epilepsy will find little difficulties in their relationships or Work, because they think people will understand their illness, regarding work, they may not have enough education that an epileptic patient must have a job that does not expose him to danger. They said that patients will not find difficulties at all in friendship, sexual, emotional, or prejudice difficulties, these answers we think some due to the fact that they did not live a lot with patients with epilepsy and they only guess that. Or due to their humble simple characters that will not deal badly with patients. Most of the participants think that people with epilepsy will feel worried, fearful, and depressed, maybe they have some education that the disease affects the life of the patient.

On the other hand, they do not think that the patients will feel dependent, incapable or ashamed, maybe because they are busy and active and they think if one gets ill that will not stop him/her from their life. Also, most of the participants do not think that prejudice against epilepsy will occur in Social relationships, marriage, School, and Indeed in the family for the same reasons.

5. Conclusion

1. More than half of participants think that epileptic patients can't pose a risk to others and they have a normal IQ.
2. Most of the participants admitted that they will not marry or let their children marry an epileptic patient while most of the participants said they will not divorce if their partner suffers from epilepsy after marriage.
3. Nearly half the participants are willing to let their children play with an epileptic child.
4. Almost all of the participants are willing themselves to participate with an epileptic patient in any social work and even have friendship with patients.
5. The majority of participants said that they will admit their illness if they have epilepsy.
6. More than half the participants think that epileptic patients are not able to control their own epilepsy at all.
7. Most of the participants will not feel shocked or fearful when they see an epileptic seizure. Meanwhile, the majority will feel sad and pity.
8. Most of the participants think that people with epilepsy will find little difficulties in their relationships and work. On the other hand, they will not have any friends, sexual, emotional and prejudicial difficulties.
9. Most of the participants think that epileptic patients are worried, fearful, and depressed. On the other hand, they don’t think that the patients will feel dependent, incapable, or ashamed.

10. Most of the participants do not think that prejudice against epilepsy will occur in Social relationships, marriage, School, and Indeed in the family.

6. Recommendations

Educational health programs and campaigns should be done both at the level of the community and clinical based to reduce the false beliefs and to eliminate stigma.

Declaration of Competing Interest

The authors declare that they have no conflict of interest.

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