

A study of Knowledge, Attitude, Practice towards Epilepsy among relative of epileptic patients in Khartoum State

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Abstract

People with epilepsy are suffering from a lot of untold negative impacts on their lives; due to misunderstanding of the disease and from the associated stigma. Objectives: The objective of this study is to assess the knowledge, attitude, and practice among relatives of Sudanese epileptic patients seen in Sheik Mohamed Kheir Neurological clinic and Elshaab Teaching Hospital.

Methods: This is a descriptive cross-sectional community based study, 313 respondents were included, the duration of the study was from November 2008 to June 2009.

Results: Most of the respondents knew the disease, and had witnessed an attack. One third mentioned a brain lesion as the underlying cause of epilepsy. Most of the respondents mentioned loss of consciousness as the major symptom. More than two thirds mentioned that it is not contagious. Most of the respondents claimed that it can be controlled, and two thirds preferred medical treatment. The study revealed that half of the respondents had shown favourable attitudes and practice. Conclusion: The study revealed that the level of knowledge, attitude, and practice towards epilepsy needs community educational programmes to fill the gaps, and minimize the stigma.

Key World: Epilepsy, Sudanese, Relative.

INTRODUCTION

Epilepsy is one of the most prevalent non communicable diseases worldwide, epilepsy is a neurological condition characterized by recurrent seizures. A seizure is a transient disturbance of cerebral function secondary to abnormal paroxysmal in the brain resulting in sudden excessive disorderly discharge of the cerebral neurons. The discharge results in almost instantaneous disturbance of sensation, loss of consciousness or psychic function, convulsive movements or some combination of these. [1-2] Persons with epilepsy are at a risk of developing a variety of psychological problems including depression, anxiety and psychosis. [3] The reported prevalence of active epilepsy in developing countries range from 5 to 10 per 1,000 people. [4] However, worldwide prevalence rate of epilepsy varies from 2.8 to 19.5 per 1,000 of the general population and is more prevalent among children.

[5] In Nigeria, the estimated prevalence of epilepsy is 8 to 13 per thousand people. [6] In developing countries the disorder is to a significant degree associated with a host of parasitic and bacterial infectious diseases that are largely absent in industrialized countries. [7]

Sociocultural attitudes continue to have a negative impact on management of epilepsy in many African countries. [8] The disorder is enrobed in superstition, discrimination and stigma in many of these countries. [9] Religious and socio-cultural beliefs influence the nature of treatment and care received by people with epilepsy. Many communities in Africa and other developing countries believe that epilepsy results from witchcraft or possession by evil spirits and therefore treatment should be through the use of herbs from traditional doctors, fetish priests and religious leaders. This contributes to deterioration of the patients' condition and development of

complications. Persons with epilepsy are shunned and discriminated against in education, employment and marriage in Africa because epilepsy is seen as a highly contagious and shameful disease in the eyes of the public. These observations came from many studies carried out in Africa. Epileptic persons suffer untold social deprivations and discrimination in education, employment, marital life and so on. [10]

OBJECTIVE

To assess the knowledge, attitudes, beliefs and practices of relative of epileptic patients towards epilepsy.

METHODS

Study design:

This is a descriptive cross-sectional community based study. Study area: Sudan is the largest country in Africa, covering one eighth of the continent surface with an area of 2.5 million sq /kms. More than 2000 km from north to south, having diverse environment due to different climatic zones, extending from the great desert to equatorial rainy forests. The study was conducted in Khartoum state with a surface area of 20140 Km and a population of 5,548,000. The state is divided politically and administratively into 7 localities and 24 administrative units. The central location of the state subjects the state to continuous population influx from other states almost on a daily bases for work, education, health services, marketing, and some for residence. It is a heterogeneous state presents people of different socio-cultural backgrounds who also are living in environments completely different from each other.

Study population:

Relatives of epileptic patients.

Inclusion criteria:

- (1) Adult relative of Sudanese epileptic patients.
- (2) Those who agreed to participate.

Exclusion criteria:

- 1) Non Sudanese.
- 2) Those bellow 18 years of age.

Sample size: Will be calculated using the formula:

$$N = \frac{z^2 PQ X deff.}{D^2}$$

D²

Where:

N: is the sample size.

Z: is the value of normal curve corresponding to the level of confidence 95%.

P: is the probability of target group 2.5%

Q: is the desired margin of error.

D: is the desired margin of error.

deff: is the design effect.

$$N = (1.96)^2 (0.025) (0.0975) (2) = \text{relative of epileptic patients}$$

$$(0.017)^2$$

Type of the sample is stratified random one.

Sampling technique:

- 1) Relative of epileptic patients will be seen personally in different neurology referral clinics in Khartoum state.
- 2) In each referral clinic the sample is going to be distributed across all the main known locations where relatives of epileptic patients are found.
- 3) In each location, every relative of an epileptic patient meeting the inclusion criteria that the data collector came across randomly was selected, till the sample for the study is completed.

Ethical Consideration:

Only adult relative of epileptic patients who agrees to participate will be included in the study, high confidentiality will be observed during filling questionnaire. Data collection: Data will be collected in the field. Inclusion criteria mentioned before will be put in mind. The adult relative of

epileptic patients will respond to the instructed questionnaire, no names will be written in the questionnaire but a code known only to the interviewer for identification if needed. All relative of epileptic patients that will be involved in the study will give a verbal consent to fill up the questionnaire. Data collection tools: This will be done through a questionnaire, this will be checked by counselor at the end of each day and subsequently coded to ease analysis, and then coded data will be entered into the prepared data sheets into the computer. Continuous variables like age will be recoded into categorical variables to aid statistical analysis. Data Analysis: The data collected as analyzed using SPSS.

Limitations of the study

The explanatory power of the study was limited by its quantitative nature: the use of structured questions does not allow for detailed exploration of the reasons why the perceivers of stigma hold particular views about a condition such as the one under investigation here. A further limitation relates to the possibility of social acquiescence in the responses obtained – informants may have answered the questions in ways they perceived as socially desirable.

RESULTS:

1. Background information:

A total number of 312 respondents were interviewed, (52.9%) were females, and (47.1%) were males. Their ages ranged between 18 to 75 years, with median age of 36 years. About (14%) are illiterate, (14%) had primary/basic education, twenty four percent had an intermediate education, (22%) had tertiary education, and (26%) post university education. Thirty six percent were full time housewives, (17%) civilian employee, (12%) self employed, 11% students, (10%) not working, (9%) labourers, and (5%) were retired employee. Sixty one percent were first degree relatives, (21%) second degree relatives, (14%) husband/wife, and (4%) were neighbours.

2. Knowledge:

The disease of the patient was known by (96.8%) of relatives. It was found that (30%) of the

respondents mentioned brain lesion as underlying cause of epilepsy followed by brain infection (20%), Heredity was identified as a cause of the disorder by (23%), supernatural power by 23%, and (4%) of the responders related the disease to other causes such as ageing process, psychological disorder, fever, and wrong blood transfusion. Regarding the symptoms of epilepsy during the attack (96.5%) of the responders mentioned loss of consciousness followed by urine incontinence (57.7%), and the patient can remember nothing after the attack (56.4%), salivation and drooling (52.2%), and biting of the tongue (44.2%), others symptoms like defecation, exhaustion, and up rolling of the eyes were mentioned by (1.9%). The provokers of the attack were mentioned by the responders as follow: fever/illness (58.7%), emotional disturbance (55.8%), flickering light (24.8%), some food and drinks (24.7%), noise (23.7%), other provokers such as drugs, hunger, and exertion were mentioned by (5.1%) of the responders. About transmission of the disease, (73.4%) said that it is not contagious, and (8.7%) mentioned that it is contagious through close contact with the patient. About control of the disease, (90%) mentioned that the disease could be controlled. It did appear that (45.3%) mentioned that it is a curable disease. Regarding the selected types of treatment to control or cure the disease as follow, modern medicine (72.8%), combination of modern medicine and religious therapy (38.8%), religious therapy (37.4%), traditional therapy (2.1%), combination of modern and traditional therapy (3.9%).

3. Attitude:

Epilepsy is a mental illness; this was mentioned by (55.4%) of responders. Regarding intelligence (64.8%) agreed that an epileptic patient is not as intelligent as a normal person. It was shown that (80.4%) agreed that an epileptic child should go to school. The study showed that (66%) of the responders agreed that an epileptic patient should be employed. About (60.8%) of the responders agreed that an epileptic patients have less chance to marry. The study showed that (84.9%) of the responders disagreed to keep the epileptic patient in the house, while (53.9%) agreed that an epileptic patient should not be socially active. It was shown that (75.1%) of the responders agreed that there is discrimination against epileptics in the community.

4. Practice:

The epileptic attacks were witnessed by 94.9% of the relatives and the following actions were done during an epileptic attack: removal of dangerous objects 88.8%, taking the patient to the hospital (86.2%), protection of the head (84%), lying the patient down (50.6%), putting an object between the teeth (49.7%), and pulling the tongue (35.9%) and to ensure good ventilation (13.7%).

5. Source of information:

It was found that (66%) of the responders got information from health workers, (22%) from friends/relatives, (9%) from TV/radio programmes, (2%) from journals, and (1%) from lectures.

Discussion

Epilepsy is usually defined as the tendency to experience recurrent seizures. The word "epilepsy" is derived from Latin and Greek words for "seizure" or "to seize upon". This implies that epilepsy is an ancient disorder. [11] Historically, epilepsy has been considered a curse of the gods, 'demonic possession,' and a form of madness. Consequently epilepsy is a condition that has been feared and rejected. [12] Misconceptions have led to social isolation for the individual with epilepsy; it is therefore no great surprise that the myths and prejudice that have surrounded epilepsy has resulted in the stigmatization of people with the disorder. [13-14] Many communities in Africa and other developing countries believe that epilepsy results from witchcraft or possession by evil spirits and therefore treatment should be through the use of herbs from traditional doctors, fetish priests and religious leaders. [15]

Because epilepsy is seen as a highly contagious and shameful disease in the eyes of the public, persons with epilepsy are shunned and discriminated against in education, employment and marriage. [16] A strong network of traditional healers was found, providing a parallel system of health care in the Sudan. People turned to religiouspiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine. The majority of people with epilepsy are in developing countries, and substantial numbers of

these people remained untreated. [17-18] The reasons for this failure of treatment are complex and involve nonpharmacologic aspects such as cultural attitudes to epilepsy, the acceptability of drugs as a method of treatment, and the less developed systems for the delivery of healthcare so continuing effective educational interventions will be of value in order to improve the appropriate understanding of epilepsy, and to ameliorate the social discrimination and misconceptions against epileptic patients. [19] Our study investigated levels of knowledge and expressed attitudes to epilepsy among relative of epileptics patients in Khartoum state. All the responders were Muslims. The group was, perhaps understandably, less well-informed about the prevalence of epilepsy, with estimates varying very widely; and significant percentages categorized epilepsy as a mental, rather than a physical, health problem although The majority of respondents harboured positive attitudes such as tolerance, kindness and sympathy towards epileptics. The belief of relating epilepsy to the supernatural is consistent with the study among Native Tribes from Central and South America by Francisco Javier et al (2006). [20] The belief of the respondents about the causes of Epilepsy and The provokers of the attack are consistent with a U.K. study researched among South Asian communities, where religious and a complementary therapy is commonly used. [21] Relatives of patients with epilepsy who don't consult a physician have a larger proportion of these wrong notions. The study demonstrated that majority of the respondents stated that epilepsy is manifested by convulsions, other manifestations of the disorder proffered by the respondents included falling down, rolling of eyes and foaming of mouth. Up to 25.2% of respondents did not know the cause of epilepsy. However some of the relatives of patients mentioned other causes of epilepsy such as heredity, brain defect, birth injury and head trauma. Overall (26%) of the respondents had good knowledge of epilepsy whereas (31%) and (43%) had fair and poor knowledge of the disease respectively.

Relatives of epileptic patients gained information from health workers, from friends/relatives, from TV/radio programmes, from journals, and from lectures. Majority of the respondents would like to have more information about the disease. Among first aid procedures removal of dangerous objects was reported by 88.8% of the responders,

taking the patient to the hospital (86.2%), protection of the head (84%), lying the patient down (50.6%), putting an object between the teeth (49.7%), and pulling the tongue (35.9%) and to ensure good ventilation (3.7%). Lack of knowledge increases the potential for inappropriate or inadequate responses by parents, teachers, coworkers, and the public at large to repetitive or prolonged seizures, and the associated discomfort about how to provide first aid also can contribute to the general stigma associated with epilepsy. Clinicians play a key role in educating patients, parents, caregivers, and the community about how to respond to an individual who is having a seizure.

Like what was mentioned in the literature the majority of the negative attitudes toward epilepsy were significantly associated with the misunderstanding of epilepsy.^[22-23] Continuing effective educational interventions would be needed in order to improve the appropriate understanding of epilepsy, and to ameliorate the social discrimination and misconceptions against epileptic patients.

Conclusion:

The study showed that the level of knowledge and understanding about epilepsy needs community educational programmes to fill the gaps, ameliorate misconceptions, and to minimize the social stigma. Those efforts will lead to acceptance of treatment, and acceptance of epileptic patients in their communities; which will reflect as a positive input in the quality of life of the patients, and their families.

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