

# The quality of life among Sudanese Patients with Epilepsy, Khartoum, Sudan

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## Research Article

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# Abstract

**Introduction:** This is the first study done in the national center for neurological sciences, Khartoum state to assess the quality of life above hundred Sudanese epileptic patients, in the period from September to December 2020.

**Methodology:** This is a descriptive cross sectional study, data was collected using interviewing questionnaire and this questionnaire was modified from SF-36 model.

**Results:** Most of the patients are from the urban area (60.2%), housewives are most of them, most of the patients were single and from low socioeconomic status, the history of the disease was less than three years for most of the cases covered in this study, most type is generalized tonic clonic epilepsy, normal EEG finding in 75.7% and normal MRI brain in 78.6%, most of patients mentioned they have no attack in last month. Regarding mental health 47.6% feel sometimes depression, 75.7% associated with memory problems. Regarding physical health 51.5% feel energetic all of the time, 9.7% always associated with sleep disturbance, most of patients are not driving, neither having hobbies for leisure time. 63.1% don't have any health problem, 32% feel stigma if attack happen in public. Commonest medication prescribed was carbamazepine and 73.8% are fully complaints with medication. 95.1% are not worried about long term medication use.

**Conclusion:** lower level of education and manual labor associated with poor quality of life, epilepsy had bad impact on social life, there is global decrease in cognitive function, most of the patients don't worry about side effects and duration of the medication usage

## Introduction

Epilepsy is a group of neurological disorders characterized by recurrent seizures that can range from short, barely detectable episodes to prolonged episodes of intense tremors caused by abnormal electrical activity in the brain. These episodes can lead to physical injury, direct fractures, or accidents. In epilepsy, seizures tend to recur and have no immediate underlying cause. Isolated seizures caused by a specific cause, such as poisoning, are not considered as epilepsy.

Seizures can occur in the cerebral cortex or subcortical structures. Using a detailed history, EEG results and additional information, the doctor can usually classify the seizure / epileptic type and then develop an appropriate treatment plan and diagnostic assessment.

Subtypes of generalized seizures are categorized as: absence, generalized tonic-clonic (GTC), atonic and myoclonic. Absence seizures (petit mal) takes the shape of staring with quality to external stimuli, typically with head cernuous or eye blinking. GTC seizures (grand mal) involves impairment of consciousness with bilateral radially symmetrical convulsive movements (stiffening followed by jerking) of all limbs. Myoclonic seizures are sudden, transient ("lightning-fast") movements however not related to any disturbance of consciousness.

(Secondary generalized epilepsy) Bilateral partial tonic-clonic seizure, which is a type of seizure that begins in one region of the brain and then spreads to both sides of the brain as a tonic-clonic seizure. Short, involuntary muscle contractions that can affect one or more muscle groups therefore, myoclonic seizures can become generalized or focal. Atonic seizures have the same effect as loss of body tone, often leading to whole body drooping or drooping of the head[1-3]. The clinical manifestations of a focal seizure depend on the area of the cerebral cortex affected. For example, a focal seizure arising from the prepsychotic cycle is manifested by asexual or tonic rhythmic locomotor activity; the occipital lobe with visual phenomena; and the posterior ileum with sensory symptoms such as paresthesia.

The seizure is assessed as dyscognitive (formerly known as advanced partial) when consciousness is impaired throughout a raptus, means the patient is unable to retort unremarkably to verbal or bit stimuli, seizures arising from the lobe are often dyscognitive. An aura precedes a focal dyscognitive or grand mal by seconds or minutes and is most frequently full-fledged by patients with temporal lobe epilepsy. An aura, could be a focal seizure whereby a patient retains awareness and describes sensory, motor, autonomic, or psychic symptoms.

The WHO has outlined QOL as “an individual' perception of their position in life within the context of the culture and worth systems within which they live and in respect to their goals, expectations, standards and concerns [4].

Quality of life is in patients with brain disorder than within the general population; it's comparable or worse in patients with epilepsy than that in patients with alternative chronic conditions; in cases of well controlled epilepsy the QOL are superb as a result of their apprehend to the matter and risk of the disease. Frequency of seizures appears to be one in all the foremost relevant determinants of poor quality-of-life (QOL) scores, quality of life become additional worse and extremely unhealthy with presence of the depression, there are not any thoroughgoing or perhaps contradictory results obtainable regarding the impact of drug treatment. Role activities, emotional standing and noesis are the foremost investigated domains of quality of life in brain disorder research, there may be a substantial lack of knowledge concerning the practical status. Currently days the {standard} of life and psychosocial functioning in folks with epilepsy have been investigated in several studies in expanded way, and no standard measures for these build terribly troublesome to be assessed precisely [5].

Epilepsy may be a common chronic neurological disease that includes a nice impact on people's lives, from such a {big amount of| such a large amount of| such a lot of} views, socially, physically [6-9].

The repeat of seizure is unpredictable and it's could cause mental injury and build the patients feel dangerous feeling like depression particularly if happened in an public area [10].

Stigma is a big drawback to epileptic patients, owing to this the patients life are going to be restricted socially, full of work difficulties, and leads to poor QOL [11-14].

In previous studies, numerous instruments were used to assess QOL in several community sectors (e.g., patients, workers, population ). One of these instruments is SF-36 questionnaire; a generic instrument translated and valid in Islamic Republic of Iran by Montazeri [15].

The data concerning QOL in very detailed manner is incredibly necessary to assist the medical employees to conduct higher services to the patients through implantation and intervention [16-21].

## Objectives

### 1 General objective:

To assess the quality of life among epileptic patients from age 18-60 and to correlate it with control of the disease.

### 2. Specific Objectives:

To assess mental health among epileptic patients.

To assess physical health among epileptic patients.

To assess the compliance of medication among epileptic patients.

To assess the life restrictions regarding daily activity, job, social status, and hobbies, among epileptic patients.

## Methodology

This is a descriptive cross sectional hospital-based study. It was conducted in the tertiary hospital of neurological science in the national neurological center clinic, is considered one of main reference teaching hospital in Sudan. In this center there is main laboratory including stem cell lab and general lab, X-ray department, blood bank, pharmacy, physiotherapy department and ICU. The NCNS center has two general wards medical and surgical with a capacity of 110 beds, 24 of them in the medical ward. The medical ward receives about 650 patients per year. There are four outpatient clinics which receive about 3000 per year referred from all over Sudan. The study was conducted within the period from September to December 2020. The sample size were 103 patients. Study population included all patients who were diagnosed with epilepsy and underwent for the hospital included in the study area within the study period, and fulfill the following criteria:

### Inclusion Criteria

Adults patient aged from 18 -60 years diagnosed with epilepsy on anti-seizures medications, visit neurological clinics in the National Centre for Neurological science, in the study area within the study time period and accepted to participate in the study.

Patients in stable clinical condition at the time of assessment.

### **Exclusion Criteria**

Not fulfill the inclusion criteria above

Less than 18 years old age and more than 60 years

Non Sudanese patients.

Patients who are Known to have secondary epilepsy due to structural disease.

### **Data collection:**

Data was collected using interviewing Questionnaire; section A: including age, gender, residence, education, occupation, marital status, socioeconomic status, family history. Section B: including quality of life (score10/10), duration of disease, type of epilepsy, EEG changes, MRI brain finding, duration of medication, attacks in last month, type of medication, single or multiple medication, complaint with medication, side effect, worry about using the medication. Section C: including mental and physical health (nervous, memory depression, concentration, energetic, sleep disturbance). Section D:social life(leisure time, driving, work, social activities), Do you worry about hurting yourself during a seizure, How worried are you about embarrassment or other social problems resulting from having a seizure in public, How good or bad do you think your health is(measured in score 100/100) . This questionnaire was modified from SF-36 model.

### **Data analysis:**

The data was analyzed by computerized program, statistical package for social sciences (SPSS),results was presented in tables and figures.

### **Ethical approval:**

A written ethical clearance and approval for conducting this research was obtained from The National Centre for Neurological Science 's ethical committee. Both verbal and written consents were taken from all participants before conducting the study. All subjects were informed that collected data was used for the research purpose only.

## **Results**

The study age groups ranged between 18 to 60 years, 61.2% of **Demographic characteristic: (Table 1):** them at the age group 18 year to 30 years, the mean age was 1.73 +/- 1.05 years, the second age group was from 31 to 40 and represent 16.5 %, 41-50years (10.7%) and last group 51 to 60 years (11.7%). Male to female ratio was 1:1.1 (46.6% male, 53.4 % female). Most of the patients from urban areas ( 60.2 %) followed by rural areas (39.8%). 41.7 % of patients were graduated only from the primary school, 11.7 %

not educated, the patients educated at universities level represent about 20.4 %, and secondary school 26.2%. Housewives are the most cases were collected in this study ( 37.9 %), labors represent 26.2 %, only 2 patients were employee (1.9%), other jobs like student teacher and others represent 34%. Most of them were single 57.3 %, 37.9 % were married and 3 cases divorced, and 1.9% are widows. Most of cases have low income ( 89.3 %), while 10.7% with middle income. Family history of same condition was relevant (18.4 %), 81.6% has no family history of epilepsy.

The self-assessment of patients about their lives was good 31.1 % ( in score **Quality of life: (Table 2):** language 10/10). Only 1 case considers himself is 1 from 10, 2.9% in 2, 6.8% in 4, 31.1% in 6, 27.2% in 8. The mean of the score to assess the quality life was 7.4 +/- 2.2.

20.4 % were more than 15 years after the diagnosis of disease, but the most of cases included in duration in less than 3 years ( 28.2 % ) and only 5.8 % in duration from 8 to 10 years, 5-8 years 13.6%, 5.8% in 8 to 10 years, and 13.6% in duration 10 to 15 years. **(Table 3)**

The most diagnosed type of epilepsy was generalized tonic clonic seizure and includes 63.1 % of cases, followed by simple partial and focal to bilateral each represents 7.8 %, and myoclonic 1%, temporal epilepsy was 5.8 %, complex partial (4.9%), absence (4.9%) and atonic 2.9%. **(Table 4)**

Only 24.3 % associated with EEG abnormality changes, 75.7% normal finding. Generalized tonic clonic Patients who they have EEG changes was generalized epileptiform discharge, temporal epilepsy associated with temporal epileptiform discharge, focal to bilateral frontotemporal epileptiform discharge. **(Table 5)**

MRI brain detects abnormality in 21.4 %, 78.6% normal. Findings of MRI were gliotic changes, infarction and mesial temporal sclerosis; mostly noticed in generalized tonic clonic and temporal epilepsy. **(Table 6)**

Duration of the treatment 41.7 % from 1 to 3 years, 16.5 % of cases from 3 to 5 years, patients more than 15 years continued on treatment represent 13.6 %, 11.7% from 5 to 8 years, 3.9% 8 to 10 years and from 10 – 15 years represent 12.6%. **(Table 7)**

Most of the patients mentioned there have no attacks of seizure 47.6 %, 36.6 % associated with 1 to 2 attacks in last month and 15.5 % associated with 3 to 5 attacks in last month. **(Table 8)**

16.5 % mentioned there become nervous personality, but 56.3 % have no change in personality. One case feels he is depressed all the time, 47.6 % feel sometimes depressed, and 40.8 % feel no any kind of depression. 75.7% mentioned there is a problem with memory. 55.4% of patients associated with difficulty on concentrating on reading. 45.6% can do any task with no problem, 54.4 % associated with problem to complete and concentrating on the task. 51.5% feel energetic all of the time and 1 % feel always tired. About 9.7 % always associated with sleep disturbance. **(Table 9\_a)**

Most of cases has no leisure time (42.7 %). 90.3 % of patients not driving. Work limitation was a lot in 46.6%, 9.7 % in most of the time and 35% don't have at all work limitation. 63.1 % have no any social

limitation. Also 63.1% have no any health problem to prevent the social activities. (Table 9\_b)

31.1 % are worrying about them self to be hurt during seizure. (Table10-a)

32 % feel embarrassment if attack of seizure happened in public. (Table10-b)

If put physical health in score from 100, most of the patients put them self in 79 +/- 14. (Table11)

The commonest medication prescribed was carbamazepine and 64.1% of patients using it, followed by Na valporate about 41.7% using it. No one use phenytoin.7.8% using Lamotrigine , Levetiracetam 12.6% , Tobriamate 1% , 27.2 % of patients on multiple medications

About 73.8 % were all of the time complaints with medication and 6.8 % a little of the time are complaints. 19.4% most of the time complaints.

25.2 % associated with side effect from the medication and most side effects were nausea9.7%, dizziness 5.8%, drowsiness 6.8% and others represents 2.9%, the 74.8% with no side effect.

95.1 % of patients were not worried about long term using of medication, 4.9% are worried.

## Discussion

This is the first study done in the national center for the neurological science, to assess the overall quality of life of Sudanese patients with epilepsy and to assess the struggles that affect their quality of life.

In our study the mean age was 22 years in comparison with study done in rural area of Chaco showed similar mean age 24.2 years [22].

In our study the gender distribution was 46.6% male, 53.4 % female, female distribution was slightly higher in comparison with study done in Paper published in Europe showed the incidence of epilepsy in gender there was no difference from male to female (1:1) [23]. In our study 41.7 % of patients were graduated from the primary school, 11.7 % not educated, the patients educated from universities represent about 20.4 % , and secondary school 26.2% we have higher level of education than in Ethiopia. Educational statuses in Ethiopia among epileptic patients were (27.6%) secondary school, (26.8%) primary school and (18.1%) have completed the university or higher studies [24].

Moreover a study done in high income area associated with higher level of the educational status, in Saudi Arabia showed the educational level in epileptic patients 68.38% male and 63.07% female studied Diploma or Bachelor education program and this associated with more compliance with treatment and awareness about their illness and in turn help them to avoid any risk factor to exaggerate the seizures attacks and this lead to better quality of life [25]. In Sweden general occupation in epileptic were manual workers (82.2%) and professionals to lesser extent (17.8%), and inspite of these results the manual worker groups at higher risk for occupational hazards than professionals job, this in turn can affect the health of patient in negative way [26]. In our study housewives are the most cases were collected (37.9

%), manual workers represent 26.2 %, professional job patients were (35.9%), this is more safe as professional jobs at lesser risk and exposure to occupational hazard than manual worker which is higher in Sweden epileptic patients. The Impact of epilepsy is negative on income and occupation of the patients, study done in Sudan showed results 17% were unemployed or had their job terminated because of epilepsy and this lead to financial difficulties to reach to anti-seizures medications [27].

In our study most of them were single 57.3 %, 37.9 % were married and 2.9% divorced, and 1.9% are widows, high level of single status reflects the stigma of social life and they believe the disease can be inherited. In china observing for 5 years had different results showed the 46.4% were single, divorce 9.1%, in china the social relation more affected than at our study done, both our study and the study done in china reflect unstable social life [28].

In our study most of cases have low income (89.3 %), 10.7% with middle income group in comparison with study done in Sweden revealed the low income group was 48.5%, middle income 31.1% and high income 20.3%, inspite of they have higher income than us they have more percentage of manual worker than us and this exposing the patients to more occupational hazard.<sup>(26)</sup> In this study family history of same condition was 18.4 %, study done by ottman et al, there is relation between epilepsy and positive parents with epilepsy and reach up to 32% [29].

In our study self-assessment of patients about their lives was good 31.1 % (in score language 10/10), in Ethiopia more than the half have good quality of life (54.8%) which is higher than our study, this results inspite of we have higher educational level so the problem may be overall satisfaction of patients about quality of life related to the health system that patients dealing with and to lesser extent to the awareness of the patients [24,30].

In our study the generalized tonic clonic seizure was higher at our study (63.1%), but same at partial (7.8%) and focal to bilateral is lower (7.8 %), Study done by T Keränen et al, Distribution of epilepsy type was 44% generalized tonic clonic seizure, 23% has partial complex seizure, 7.5% simple partial seizure and 25.5% with focal to bilateral seizures [31].

In our study only 24.3 % associated with EEG abnormality changes, 75.7% normal finding, this opposite to other study 75% showed there EEG changes [32]. In this study MRI brain detects abnormality in 21.4 %, and 78.6% normal, In other study done by Cendes F et al, showed the positive finding in MRI of epileptic patients was 40% [33].

Duration of the treatment 41.7 % from 1 to 3 years, 16.5 % of cases from 3 to 5 years, patients more than 15 years continued on treatment represents 13.6 %, 11.7% from 5 to 8 years, 3.9% 8 to 10 years and from 10 – 15 years represents 12.6%. In our study most of the patients mentioned there have no attacks of seizure 47.6 %, 36.6 % associated with 1 to 2 attacks in last month and 15.5 % associated with 3 to 5 attacks in last month. Other study results In Ethiopia reported seizure frequency attack was 1 in 14.2% per month, 2 attacks in 13.4%, 3 attacks per month in 7.6% and about 60% free from attack, generally the

we have higher educational level but in Ethiopia have better quality of life this associated with same attacks and same level of controlling of disease [34].

In our study 16.5 % mentioned there become nervous personality, but 56.3 % there have no change in personality. Study done by Gnanavel et al, showed depression is high in epileptic patients reach up to 55% [35]. Same results in our study, one case feels he is depressed all the time, 47.6 % feel sometimes depressed, and 40.8 % feel no any kind of depression, In our study 75.7 % mentioned there is a problem with memory, 55.4% of patients associated with difficulty on concentrating on reading, 45.6 % can do any task with no problem, 54.4 % associated with problem to complete and concentrating on the task, in comparison with study done by Hermann and Seidenberg et al. showed there is global decrease and impairment of the cognitive function in 47% of cases [36].

In our study 51.5 % feel energetic all of the time and 1 % feel always tired, About 9.7 % always associated with sleep disturbance, in another paper done by Bjrholt et al. showed generally overall lower level of physical activity than our study [37].

In our study most of cases have no leisure time (42.7 %), in other study showed the leisure time was 23%. Work limitation was 46.6 % in a lot of the time, but 35% has no any limitation in work, in other study work limitation was 42% [38].

In our study 63.1 % has no any social limitation, Also 63.1% has no any health problem to prevent the social activities, 31.1 % are worrying about them self to be hurt during seizure, 32 % feel embarrassment if attack of seizure happened in public. if this compared with previous study done in Sudan 58% had no any social activities, 15% feel stigma with the epilepsy, and this study mentioned the injury during seizures were 52%.<sup>(27)</sup>If put physical health in score from 100, most of the patients put them self in 79 +/- 14, similar results in study done by Volpato et al [38].

In our study the commonest medication prescribed was carbamezapine and 64.1% of patients using it, followed by Na valporate about 41.7% using it, No one use phenytoin.7.8% using lamotrigine. Levetiracetam 12.6% Tobriamate 1% , and 27.2 % of patients on multiple medications. In India Monotherapy and polytherapy with two and greater than or equal to three AEDs were prescribed in (37.9%), (34.9%) and (27.2%) patients, respectively [39]. In Ethiopia (63.41%), of the participants were taking two antiepileptic medications and associated with more side effects [40]. In Ethiopia the medications used were Phenobarbital (67%) and phenytoin (33.3%) were the most frequently prescribed [41]. In our study about 73.8% were all of the time complaints with the medication, 6.8% a little of the time complaints and 19.4% most of the time complaints. In Ethiopia (32%) of the participants were adherent to their treatment, The most common reported reasons for non-adherence were forgetfulness 49(75.4%) and run out of pills 7(10.8%), we have higher percentage of compliance this may be due to more percentage of the monotherapy than polytherapy in our patients [40].

In our study 25.2 % associated with side effect from the medication and most side effects was nausea 9.7%, dizziness 5.8%, drowsiness 6.8% and others represents 2.9%, the 74.8% with no side effect,

when comparable with previous study done in Sudan showed same side effects of medications 26% experienced one or more side effect [27].

Moreover in India showed different side effect, Nausea 5.3%, dizziness 5.6%, drowsiness 40.1%, memory problem 30.3%, headache 28%, tiredness 34%.<sup>(39)</sup>In our study 95.1 % of patients were not worried about long term using of medication, 4.9% are worried, in comparison with study done in Ethiopia they are more worried in using the anti-seizures medications than in our study, about 67.4% are worried from using the medications for long time [41].

## Conclusion

Most of epileptic patients are housewives, Lower level of education and manual labor are both associated with poor quality of life, especially manual labor exposed to more occupational hazard than professional job and this has negative impact on income. Epilepsy Have bad impact on social life. The most common type of epilepsy in our study is generalized tonic clonic seizure. The majority of epileptic patients have normal EEG ,Depression rate in our study was similar as in international studies .In our study there is global decrease in cognitive function, which is similar worldwide. The complaints with medication in our study was good. Most of patients in our study don` t worry about medication side effects and long duration of medication.

## Declarations

Ethics approval and consent to participate :

Written consent to publish this information was obtained from the patients.

### Consent to publish:

All the authors are agree to publish the paper in the African journal and middle east epilepsy Journal.

### Availability of data and materials:

The datasets used and \ or analyzed during the current study are available from corresponding author on reasonable request.

### Competing interests:

The authors have no conflict of interest to declare.

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## **Authors contributions:**

All authors read and approved the final manuscript .

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## **Abbreviations**

QOL: Quality of life

NCNS: National center of Neurological Sciences

ILAE : International league Against Epilepsy

MRI: Magnetic Resonance Imaging

SPSS :Statistical package for Social Sciences

N: number

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## Tables

Tables 1-11 are available in the Supplementary Files section.

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