



QUALITY OF LIFE OF PERSONS WITH EPILEPSY AMONG ADOLESCENTS AND ADULTS USING TWO MAJOR HOSPITALS IN THE GAMBIA

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Abstract

Objective: Epilepsy is a significant public health problem globally. The social stigma and impact on quality of life (QOL) may pose a bigger challenge than the clinical entity. In The Gambia, there are no studies on the QOL in patients with epilepsy. This study was conducted to determine the health-related QOL (HRQOL) of patients with epilepsy in two selected hospitals in The Gambia.

Materials and methods: This was a cross-sectional, questionnaire-based study conducted over three months (July 30th to October 30th, 2023). Adolescents aged 18 years and above and adults with a diagnosis of epilepsy were included in the study. The Quality of life in Epilepsy-31 (QOLIE- 31) tool was used to collect data on HRQOL in the study

Results: The QOLIE- 31 score of the 78 patients with epilepsy ranged from 27 - 98 with a mean (standard deviation) score of 63 (16.32). Two (2.6%) patients had scores ranging from 91 - 100 (excellent quality of life); 12 (14.4%) had scores ranging from 81-90 (very good quality of life); 14 (17.9%) scored 71 – 80 (good quality of life); 16 (20.5%) had scores ranging from 61 – 70 (regular quality of life). Thirty-four (43.6%) had a poor quality of life (scores ≤ 60).

Conclusion: Almost half of the participants (43.5%) had poor QOL, and the single most important factor was seizure worry. Hence, pragmatic psychological effort should be made to reduce stigma associated with epilepsy.

Keywords: Adolescents, Adults, Epilepsy, Gambia, Quality of life, Person's with epilepsy.

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INTRODUCTION

Epilepsy is one of the most common serious neurological disorders affecting about 65 million people as of 2015^[1]. It affects 1% of the population by age twenty and 3% of the population by age seventy-five^[2]. It is twice more common in males than females^[3, 4]. Most of those with the disorder (80%) are in low-income populations^[5] or the developing world^[6] like Sub-Sahara Africa. Epilepsy causes repeated seizures. It can be a lifelong condition. A person with epilepsy (PWE) is faced with many challenges in Sub-Sahara Africa, including The Gambia. Some of these challenges include beliefs like; Persons with epilepsy (PWEs) have insanity; epilepsy is a spiritual disease, epilepsy is transferable, PWEs should be withdrawn from school, PWEs cannot excel in life and cannot participate in sports, PWEs should not play with normal people; PWEs should be treated by traditional healer, and many others.

Epilepsy has long been recognized as a condition generally associated with a significant burden of health-related stigma^[10-12]. Stigma associated with epilepsy continues to be significant in both developed and developing countries^[4]. Nowhere is epilepsy-associated stigma more disabling than in sub-Saharan Africa (SSA) possibly due to fear contagion^[13-15]. Stigma in SSA extends beyond the individual to family members and other close associates of PWEs. This is referred to as courtesy stigma^[14, 18]. The person with epilepsy is therefore socioeconomically disadvantaged due to discrimination in employment and educational opportunities. In addition, there is also the risk of abandonment by spouse and/or family and increased vulnerability to rape and physical abuse. In Africa, epilepsy may be used as justification to deny marriage. In fact, some people still believe that persons with epilepsy are cursed^[3].

In parts of Africa, such as Nigeria, Uganda, and The Gambia, epilepsy is claimed to be associated with possession by evil spirits, witchcraft, or poisoning and is incorrectly believed by many to be contagious or transferable^[3,19,20]. In epilepsy, seizures tend to recur and may have no immediate underlying cause^[21]. These episodes can result in physical injuries, either directly such as broken bones or by causing accidents^[6].

The Quality of Life (QOL) is a concept, which is understood as the degree of general well-being that a person reaches in his physical, mental and social aspect. In patients with epilepsy, this is compromised because it is a chronic disease that influences the patient's daily life, both personally and socially^[7].

This study examines the impact of epilepsy on learning, school attendance, employment, relationships, and social interactions. It also examined factors associated with poor quality of life among PWEs in the study areas. The data generated will serve as baseline to develop appropriate steps or measures to enhance the quality of life of persons with epilepsy and persons with epilepsy syndrome through education of family members and society at large. The provision of appropriate management, community participation with health care providers, and support groups will lead to reduced stigmatization.

METHODOLOGY

This hospital based prospective cross-sectional study was carried out using the two main hospitals in The Gambia - **Edward Francis Small Teaching Hospital (EFSTH) and Kanifing General Hospital (KGH)** from July 30th to October 30th, 2023. These two main health facilities are located in the Western Health Administrative Region of The Gambia. Gambia is a small West African country with a population of 2.4 million people as at 2024. EFSTH and KGH are the two largest hospitals in the country and as such, the main referral centers.

EFSTH is a tertiary referral hospital in Banjul, the capital city of The Gambia. It is the largest hospital in the country with 540 beds, originally founded by British colonialists in 1853. Not until 2013, it was known as the Royal Victoria Teaching Hospital (RVTH). KGH is a secondary referral hospital for many of the country primary health facilities which was officially inaugurated in 2014. It has a bed space of about 130.

Study population

Seventy-eight (78) consecutive patients who presented to the clinic within the period of data collection were recruited for the study. The subjects included both male and female adolescents and adults aged ≥ 18 years with a diagnosis of

epilepsy, based on physician-diagnostic criteria with/without electroencephalogram (EEG). Included in the study were all PWEs aged 18 - 80 years who presented to EFSTH and KGH for their routine clinic visit, or those who presented with seizure during the study period (July 30th to October 30th, 2023) and those that gave written informed consent. Those whose presentation is not consistent with the definition of epilepsy (provoked seizure) and those who do not give consent were excluded from the study.

Epilepsy was defined as follows;

1. At least two unprovoked (or reflex) seizures occurring >24 hours apart
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years
3. Diagnosis of an epilepsy syndrome

Epilepsy is considered resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years [8,9].

Data collection

After confirmation of the diagnosis of epilepsy by the neurologists and fulfilling the inclusion criteria, patients completed the Quality of Life in Epilepsy-31 inventory (QUOLIE-31) questionnaire either at the time of diagnosis or during routine clinic visit [30] at EFSTH and KGH. QOLIE-31 has not been validated or translated to any local language in The Gambia yet, but persons with epilepsy who cannot speak or write English are adequately translated to by either an educated family member who escorted them to clinic after explaining QOLIE-31 content and meaning with obtained informed consent or any of the indigenous health workers who participated in the study. The process involved distributing the questionnaire to those who understand English to fill out their responses while those who doesn't understand English are assisted to fill out the questionnaire following their respective responses. Scores ranged from 0 to 100, and a higher score shows better quality of life (QOL) while a lower score shows poor quality of life. The scores obtained in the questionnaire were converted into a scale of

0 to 100 points, with tables and mathematical operations previously designed for this questionnaire. The sum of the scores of each domain gives the global score, which indirectly reflects the quality of life of the person. These variables were entered into a standard variable collection sheet, which also contained the patient's socio-demographic data (age, sex).

Data collection tools

A structured Questionnaire (QUOLIE-31) was used to obtain data from the patient or family being interviewed. QOLIE-31 is a questionnaire that consists of 31 items and 7 subscales: emotional well-being, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects, and overall quality of life. The overall score of the patients was obtained using a weighted average of the above scale. The QUOLIE-31 also includes a single item that assesses overall health. Patients with higher scores after calculating the average of the scales have a good QOL compared to those with a low average scale (poor QOL). To account for these differences, the scoring procedure for the questionnaire (QUOLIE-31) first converts the raw pre-coded numeric values of items to 0 - 100-point scores, with the higher converted scores always reflecting a better QOL. The overall score of each patient was derived by weighing and summing the QUOLIE-31 scale scores. QUOLIE-31 scale weights were derived from a regression analysis that used a summary score from QUOLIE-89.

Data analysis

Data were analyzed using software SPSSv20. The means, standard deviation, and percentage scores were recorded. The Pearson product-moment correlation coefficient was used to study the correlation between each QUOLIE-31 subscale and the overall percentage score. Quality of Life was categorized as follows: excellent QOL (91-100); very good QOL (81-90); good QOL (71-80); regular QOL (61-70); poor QOL (≤ 60).



RESULTS

Table I: Sociodemographic characteristics of the subjects

| Sociodemographic variables | Frequency (N) | Percent (%) |
|----------------------------|---------------|-------------|
| Age group | | |
| 18-24 | 18 | 23.1 |
| 25-34 | 28 | 35.9 |
| 35-44 | 21 | 26.9 |
| 45-54 | 6 | 7.7 |
| >54 | 5 | 6.4 |
| Sex | | |
| Male | 43 | 55.1 |
| Female | 35 | 44.9 |

Seventy-eight (78) questionnaires were administered. The responsiveness level of participants was 100%. The age range of patients was 18–80, with a mean (SD) age of 33 years. Forty-three participants (55.1%) were males, and thirty-five participants were females (44.9%), as shown in Table I.

A descriptive table combines the data from the age and sex categories, indicating the mean age of the study in a population sample of 78 PWEs with ages ranging between 18-80 years; the percentage of sex that participated in the study indicates the distribution that more males participated in the study than females.

Table II: Descriptive statistics in quolie-31 inventory

| Subscale of QUOLIE-31 | N | Mean | SD | Pearson correlation with overall % score |
|--------------------------|----|------|------|------------------------------------------|
| Seizure worries | 78 | 48.6 | 24.8 | $r=0.680$ ($p=0.000$) |
| Overall quality of life | 78 | 55.9 | 22.8 | $r=0.742$ ($p=0.000$) |
| Emotional wellbeing | 78 | 61.3 | 15.7 | $r=0.715$ ($p=0.000$) |
| Energy/fatigue | 78 | 62.6 | 16.3 | $r=0.385$ ($p=0.000$) |
| Cognitive functioning | 78 | 57.3 | 25.4 | $r=0.854$ ($p=0.000$) |
| Medication effect | 78 | 66.0 | 17.0 | $r=0.521$ ($p=0.000$) |
| Social functioning | 78 | 74.2 | 16.8 | $r=0.702$ ($p=0.000$) |
| Overall percentage score | 78 | 63.0 | 16.3 | |

It is evident from Table II that QUOLIE-31 subscale with the highest mean is social functioning (74.24; SD=16.756) while the lowest mean is seizure worry (48.63; SD=24.791). It is also evident from the table that there is a significant correlation between each subscale of QUOLIE-31 and overall percentage score.



Table III: Overall average score QOL

| QOL Score | QOL Categories | Frequency (N) | Percent (%) |
|-----------|---------------------------|---------------|-------------|
| 91-100 | Excellent quality of life | 2 | 2.6 |
| 81-90 | Very good quality of life | 12 | 15.4 |
| 71-80 | Good quality of life | 14 | 17.9 |
| 61-70 | Regular quality of life | 16 | 20.5 |
| ≤60 | Poor quality of life | 34 | 43.6 |
| TOTAL | Overall Score | 78 | 100.0 |

The range of scores was from 27 - 98 with a mean score of 63 (SD=16.32). On the percentage score scale, two persons had scores that ranged from 91 -100 (2%); 12 persons scores range from 81-90 (15.4%); 14 persons scores range from 71 - 80 (17.9%); 16 persons scores range from 61-70 (20.5%); 34 (43.6%) persons scored ≤ 60%, as shown in Table III.

Table V: List of Abbreviations

| S/N | Abbreviation | Full Meaning |
|-----|--------------|----------------------------------------|
| 1 | QOL | Quality of life |
| 2 | HRQOL | Health- related quality of life |
| 3 | QUOLIE-31 | Quality of health-31 |
| 4 | PWE | Persons with epilepsy |
| 5 | EFSTH | Edward Francis Small teaching hospital |
| 6 | KGH | Kanifing General hospital |
| 7 | RVH | Royal Victoria hospital |
| 8 | EEG | Electroencephalogram |

Table IV: Predominant QUOLIE-31 factor in Persons with poor quality of life (≤ 60%)

| QUOLIE-31 Subscale | POOR QOL | GOOD QOL |
|-----------------------------------------------------|-----------|-----------|
| <i>Persons with single factor subscale</i> | | |
| Seizure worry | 20 | 3 |
| Overall quality of life | 4 | 3 |
| Emotional wellbeing | 2 | 1 |
| Energy/Fatigue | 1 | 4 |
| Cognitive | 4 | 3 |
| Medication effect | 0 | 5 |
| Social function | 0 | 22 |
| <i>Persons with equal score for > 1 subscale</i> | | |
| Seizure + Cognitive functioning | 2 | 1 |
| Overall QOL + Energy/Fatigue | 1 | 0 |
| Overall QOL + Medication effect | 0 | 1 |
| Cognitive + Social function | 0 | 1 |
| TOTAL (single + multiple factors) | 34 | 44 |

Out of the 34 persons with poor quality of life, twenty (58.82%) persons stated that their main concern was seizure worry; four (11.64%) persons stated their overall quality of life as not been good when asked to scale from 0-10; two (5.82%) persons stated that their emotional wellbeing is affected and has been there concern; while none were concerned about their medication effects or social function. Also, three (8.82%) persons stated that their main concern was beyond one factor on QUOLIE-31 subscale. There were two (5.82%) persons who were concerned about seizure worry and cognitive function impairment; while one



(2.94%) person has problem with overall quality of life scaling has been poor and having lack of energy/fatigue.

On the other hand, those with good or excellent quality of life show that one or more factor(s) has been a contributing factor to their improved health. Three (8.82%) persons stated that they are never worried about seizure attack. Three (8.82%) persons stated their overall quality of life is better according to their scaling on a scale of 0-10. One (2.94%) person stated to have been in an excellent emotional state. Four (11.64%) persons are full of energy and are not often feeling fatigue; another three (8.82%) persons never had problem with their cognitive ability; five (14.56%) persons demonstrated they are never worried about their medication effects; while twenty two (64.7%) persons stated their social function is better and are never worried about attack in any social activities including going to parties, visiting friends and family, attending meetings etc. three persons stated their overall quality of life because their responses involve more than one QOLIE-31 subscale; one person stated to be never worried about seizure attack and cognitive ability is never impaired; one person rated his/her overall quality of life to be good and never worried about medication effects; one person stated to have excellent cognitive ability and never worries about social activities.

DISCUSSION

Epilepsy has a considerable impact on QOL with extensive and life-long consequences. Improving the QOL in a person with a seizure disorder is an essential component of the management of such persons. The mean total score of QOLIE-31 in this study was almost similar to a survey conducted in India (64.61) ^[22] higher than studies conducted in Australia (52.9) ^[23], but is consistent with the global mean

QOLIE-31 score: 59.8 ± 8 ^[24]. A study in Malaysia has reported a higher mean total score of QOLIE-31 (68.9) ^[25]. Even though most of the studies had used the QOLIE-31 questionnaire (different translations), different study methodologies with different inclusion and exclusion criteria would have accounted for the different scores. Higher score as reported in this study reflects a better standard of medical care.

The pattern of scores of QOLIE-31 subscales of this study was partially similar to the studies conducted in Malaysia ^[25]. In this study, the social functioning subscale was highest, and seizure worry the lowest which is similar to the study conducted in Qassim region of Saudi Arabia ^[26] which also has social function as the highest domain score, and seizure worry was the lowest domain scores. The difference in pattern may be due to the reason that different countries have dissimilarities of beliefs, culture, and socioeconomic factors, which in turn can affect QOL measures, thus findings from other countries, may not be relevant to the local situation we have here in The Gambia.

A study reported that seizure frequency was the single most important clinical predictor of psychosocial dysfunction and emotional maladjustment in epilepsy patients ^[27]. A study done by Saadi et.al ^[24] compared the total QOLIE score globally. They reported that Russia and Canada with 42.1 and 82 scores had the lowest and highest recorded scores respectively.

In this study, it was shown that only two persons (2.6%) had excellent quality of life; 13 persons (16.7%) has very good quality of life; 13 persons (16.7%) has good quality of life; 16 persons (20.5%) has regular quality of life; 34 persons (43.6%) had a poor quality of life. In a study conducted in



Vietnam^[28], it was concluded that the overall QOL of PWE is moderate with a mean score of 71.3% which was higher than this study (63) probably due to the small sample used for the study (58), disparity in culture and social attitude of Vietnamese people.

From the study, it was evident that the major factor contributing to poor quality of life in PWEs is seizure worry; this may be because of the stigma associated with seizure. In addition, some assume that they were not born normal and therefore should not involve or do what others does. Others stated that they do not have the resources to purchase their medications as needed, which made them worry about having an attack unexpectedly. Hence good seizure control will reduce the seizure worry and consequent better QOL. This is similar to a study conducted in Vietnam^[28] in which seizure worry was a significant factor contributing to poor quality of life, which was related to the increased frequency of seizure in an epileptic person and its effect on cognitive function.

It is also evident from this study that the major contributing factor that led to an improved quality of life in this category was improved social functioning. In the same study in Qassim region of Saudi Arabia^[26] education is a major contributor to an improved QOL in that educated PWE are more likely to have a better understanding of their disease, seizure-triggering factors, and seizure management, which contribute to adherence to medication.

As in many countries, epilepsy negatively affects the QOL of Gambia patients. Seizure worry is the single most important factor affecting PWE daily activities. Current study results have encouraged the application of behavioral intervention in practice. Therapists should consider other factors, as well as QOLIE-31 and its domains, thereby

adapting therapy to the specific factor(s) affecting their functioning. Adding clinical counseling and other interventions to address the physical, mental, psychological, social, and emotional aspects of health well-being is likely to achieve better health outcomes for epilepsy patients. Raising awareness in society regarding the existence of effective therapy through public educational campaigns might help in eliminating the stigma of epilepsy and may improve QOL of epilepsy patients. It is obvious that QOLIE-31 overall score is under the influence of cultural, social, and economic factors^[29]. Higher QOLIE-31 score in a country represents better information about the disease, decrease in stigma, social support and patients' education and awareness about the disease and self-care. A lower score, such as those in this study and in Bhutanese indicates that more education and awareness about the disease is necessary. Therefore, it seems that further QOL related studies are needed in developing countries.

Study limitations

Few numbers of patient studied and the short period of data collection limit this study. Future studies should involve multiple centers, more study participants and longer duration for the sample collection.

As the QOL in PWEs can be considered a reflection of cultural, social, and disease-related factors, we suggest that it is up to the health-care system to give information and educate PWE and the society about the possible overwhelming factors, which may affect the QOL in epileptic persons. In addition, adding clinical counseling and other interventions to address the physical, mental, psychological, social, and emotional aspects of health well-being is likely to achieve better health outcomes for epilepsy



persons. To remove the stigma with epilepsy and improve QOL of persons with epilepsy, raising the awareness in society regarding present effective therapy by public awareness and educational campaigns may be helpful.

The type of drug therapy followed by a patient with epilepsy plays a very important role. Persons who were on monotherapy had a better QOL mainly because of the lesser side effects as compared to those on polytherapy. A multidisciplinary management of these persons is required, with the objective not only of achieving total control of the seizure crises but also of the patient having the tools to overcome daily the impact that this disease generates on their quality of life.

CONCLUSION

While the impact of epilepsy on the QOL is by now a common knowledge in various parts of the world, countries like The Gambia has no study to know the impact of epilepsy on its citizens and which factor play the most significant role in negatively affecting PWE. It is evident that almost half of the participants had poor QOL with the major contributing factor to this been seizure worry- with most stating that they often worry about the stigma attached with an attack especially in public gatherings. This limits their desire to participate in various activities involving social gathering, ceremonies, sports, schools, marriages etc., and this made them to distant themselves from their environment.

RECOMMENDATIONS

Organizing frequent awareness to the general populations about epilepsy and interactions with PWEs can reduce the stigma on those with the condition. Reducing cost of antiepileptic medications, easy access to healthcare for PWE

can positively influence their QOL. Providing free education, enhancing participation in sport will positively change their perspective about themselves.

Ethics approval

Approval to conduct the research was granted by *Research Ethics Committee (REC) Edward Francis Small Teaching Hospital Banjul, The Gambia* with reference number **EFSTH_REC_2023_079**. All participants gave consent; Confidentiality was ensured. The questionnaires and any other relevant document gathered from the research were stored in a password protected computer or locked in a store where access is limited for future use.

Consent: Consent was granted by participants before conducting the study and by all participants and authors for publication

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