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RESEARCH ARTICLE

Quality of life of people with epilepsy at a tertiary referral centre in Goma, in the DRC

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Abstract: Purpose: This study aims to determine the quality of life (QOL) related to the health of people with epilepsy (PWE) followed in ambulatory care at the Neuropsychiatric Hospital Center in Goma, in the Democratic Republic of the Congo. **Methods:** A total of 302 adults with epilepsy followed in ambulatory care at the Neuropsychiatric Hospital Center in Goma were interviewed in this cross-sectional study. The QOL was measured using a validated French-language version of the Quality of Life in Epilepsy-31 inventory (QOLIE-31). **Results:** The mean age was 28.4±11.0 years and 56.9% were males. The mean total QOLIE-31 score was 47.7±11.0. The highest subscale score was overall QOL with a mean of 57.5±15.0 and the lowest was medication effects with 39.7±27.5. Unemployment, presence of seizures, tobacco use, and co-morbidities (medical or psychiatric) significantly affected QOL ($p < 0.05$). All QOL subscales showed a significant correlation with seizure frequency, except for medication effects. **Conclusion:** Worrying about seizures had the major contribution to QOL, while the medication effects had the least. This study confirms the importance of seizure control for better QOL in Congolese PWE.

Keywords: quality of life, epilepsy, QOLIE-31, Goma

1 Introduction

Epilepsy is a very common chronic neurological pathology, its clinical severity is very varied, ranging from benign idiopathic epilepsy of favorable development to extremely severe epileptic encephalopathy [1, 2]. About 70% of epilepsy stabilizes well with or without treatment and 20-30% are drug-resistant with possible significant impact on patients' quality of life (QOL). The occurrence of a seizure does not necessarily endanger the life of the patient, but the prognosis of epilepsy is mainly based on its consequences on cognition, psychological state, schooling, socio-professional activity, and family life of the patient [3, 4], knowing that epilepsy often begins at a young age and affects young people in their most productive years of life and may affect their social and cognitive development [1, 5].

According to the World Health Organization (WHO), around 50 million people worldwide have epilepsy, making it one of the most common neurological conditions. About 80% of people with epilepsy (PWE) live in low- and middle-income countries where the rate of new cases is up to twice as high as in high-income countries where the annual incidence is between 30 and 50 per 100,000 inhabitants [6]. The prevalence of epilepsy in Sub-Saharan Africa (SSA) at nine per 1000 people (95% CI: 8.0-9.9 per 1,000 persons) for active epilepsy and 16 per 1,000 persons (95% CI: 12.3-19.7 per 1,000 persons) for lifetime epilepsy [7]. It is estimated that more than 800,000 people in the Democratic Republic of the Congo (DRC) suffer from epilepsy [8], but there is a lack of data on the current prevalence of epilepsy in the DRC [1, 5].

There is a considerable disparity in the quality of care for PWE, between developed and developing countries, and between urban and rural areas in the same country [9]. Epilepsy is still little known to the public, and raises several questions about its etiology and management in Africa. In SSA, many PWE live in hiding because of the disease's social burden. Epilepsy is associated with stigma and mistaken beliefs associated with different socio-cultural representations of the disease that cannot be changed by scientific knowledge [1, 10]. These beliefs, perceptions, and apprehensions differ from country to country and may influence the attitudes of patients

and their families to care options (conventional or traditional medicine). This socio-cultural and economic environment in which PWE live in Africa and the DRC in particular can have a negative impact on the PWE's QOL. QOL is a concept that is influenced by the patient's physical health, psychological state, level of independence, and social relationships. The QOL in PWE remains an important area of research and evaluation should focus not only on seizure assessment, but also on other areas of life such as cognitive, emotional, socio-professional functioning, health perceptions, and general life satisfaction [11]. The recognition of this multidimensional nature of QOL has also been reflected in the three to six areas that usually make up its assessment [12]. In this study, physical health, psychological, social and environmental relationships were used in the evaluation of QOL in PWE.

Very few studies have been conducted on epilepsy and none have been published on the measurement of QOL in PWE in the DRC. This study was conducted to determine the level of health-related QOL of PWE being followed in ambulatory care at the Neuropsychiatric Hospital Center in Goma, in the DRC.

2 Materials and methods

2.1 Study framework and design

This cross-sectional study was conducted at the Neuropsychiatric Hospital Center in Goma, in the North Kivu province, eastern DRC (city with about 2 million inhabitants). This hospital is the only hospital in North Kivu province to provide specialized services in neuropsychiatry care and has a bed capacity of 100 patients. The prevalence of epilepsy in the community is unknown.

2.2 Study population and data collection

This study included all adults ($\geq$ 18 years of age) epileptic patients enrolled for follow-up at the Neuropsychiatric Hospital Center in Goma from March to April 2022 diagnosed with epilepsy and/or a history of use of anti-epileptic drugs. We included all types of epilepsy that had been diagnosed for at least one year; respondents were also required to be seizure-free for 24 hours and agreed to participate in the study. Patients excluded from the study were those for whom there was insufficient data regarding the diagnosis or incorrect diagnosis of epilepsy. Data were extracted from medical notes using a questionnaire developed and prepared for statistical analysis.

The available medical notes were reviewed manually and the following information was obtained using an elaborate questionnaire with a number of variables: socio-demographic data (age, gender, marital status, employment status, educational level, and religion), alcohol consumption, tobacco use, family history of epilepsy, clinical features of epilepsy (frequency, type of seizures, duration of epilepsy), and antiepileptic medication. The frequency of seizures was defined as the number of seizures that occurred in the four weeks prior to the interview. We also collected data on the medical co-morbidity of other chronic diseases such as diabetes, hypertension, and respiratory problems.

Quality of Life in Epilepsy-31 inventory (QOLIE-31) was used to collect QOL data and consists of seven sub-scales: seizure worry (five items), emotional well-being (five items), energy/fatigue (four items), cognitive functioning (six items), medication effects (three items), social functioning (five items), overall QOL (two items), and one subjective overall health item [13]. Responses used Likert scales that were then transformed into linear scales from 0 to 100. A higher score indicates better QOL.

We used the French version of QOLIE-31 [14]. A pre-test was performed on 20 PWE to ensure that the translated questionnaire was easy to understand. The scoring and weighting of each element of QOLIE-31 were obtained from the QOLIE-31 guidelines [13]. Total scores of sub-scales are presented in the results section.

2.3 Statistical analyzes

Data entry and processing was performed using STATA version 16 software. Descriptive analysis was performed using proportions calculations for qualitative variables (frequencies and percentages) and means with standard deviation (SD) for quantitative variables. The independent t-test or the one-way analysis of variance (ANOVA) was used to compare the means of QOL scores between groups. The correlation coefficient was used to measure the relationship between seizure frequency and the total QOLIE-31 score.

2.4 Ethical considerations

This study has been approved by the Medical Ethics Committee of the University of Goma (Approval No: UNIGOM/CEM/002/2022). Free and informed consent was obtained orally from each participant prior to the interview after providing a brief explanation of the study. Each

participant was also informed that they have the right to refuse or withdraw their participation at any time and that no prejudice will be imposed as a result of their participation or refusal. At the time of data collection, personal identifiers such as the names and telephone numbers of study participants were never recorded. The data collected were kept confidential and used only for the purpose of the study.

3 Results

3.1 QOLIE-31 score

The mean scores (SD) of the QOLIE-31 subscales are presented in Table 1. The mean total score of QOLIE-31 was 47.7±11.0. The lowest mean score was the medication effects subscale with 39.6±27.5 and the lowest was the overall QOL subscale with 57.5±15.0. The one-way ANOVA test showed significant differences in the mean score of the QOLIE-31 subscales (test F=8.294; $p < 0.001$). Table 1 also shows the Cronbach alpha results for each subscale.

Table 1 Total score of QOLIE-31 sub-scales

Subscales of QOLIE-31	Mean (SD) score	Cronbach's alpha
Seizure worry	41.48 (20.48)	0.832
Overall quality of life	57.54 (15.02)	0.809
Emotional well-being	51.74 (13.75)	0.803
Energy/fatigue	52.31 (12.03)	0.818
Cognitive functioning	45.08 (18.02)	0.805
Medication effects	39.65 (27.49)	0.855
Social functioning	52.2 (16.89)	0.804
Subjective overall health (item 31 – visual analogue scale)	47.02 (24.95)	0.816
Total score	47.73 (11.00)	0.763

Note: One-way ANOVA, F test = 8.294, $p < 0.001$.

3.2 Socio-demographic characteristics of the respondents

A total of 302 PWE participated in the study with a response rate of 100%. The mean age of the participants was 28.4±11.0 years, and most of the 135 (44.7%) were between 18 and 24 years of age. More than half (56.9%) of the respondents were men. Half (151/302) of the participants had reached a secondary school level. More than half (53.3%) of the participants were Protestant. Two hundred and twenty-nine (75.8%) participants were single and more than one third (18.2%) were employed (Table 2).

Table 2 Differences of QOL score for socio-demographic characteristics of the respondents

Variable	Total (N = 302) n (%)	Total QOL score Mean (SD)	p-value
Age			0.380*
18-24 years	135 (44.7)	46.4 (11.3)	
25-29 years	81 (26.8)	48.8 (10.4)	
30-34 years	28 (9.3)	48.3 (10.6)	
35-44 years	32 (10.6)	49.9 (12.4)	
$\geq$ 45 years	26 (8.6)	48.0 (9.7)	
Gender			0.499**
Female	130 (43.1)	47.2 (10.8)	
Male	172 (56.9)	48.1 (11.2)	
Educational level			0.351*
Illerate	67 (22.2)	46.4 (10.7)	
Primary	84 (27.8)	47.3 (11.5)	
Secondary	123 (40.7)	48.1 (10.8)	
Higher/University	28 (9.3)	50.7 (10.9)	
Marital status			0.950*
Married	60 (19.9)	48.1 (10.9)	
Single	229 (75.8)	47.7 (11.1)	
Divorced/Widowed	13 (4.3)	47.1 (10.0)	
Religion			0.062*
Catholic	126 (41.7)	46.5 (10.2)	
Protestant	161 (53.3)	48.2 (11.2)	
Others	15 (5.0)	53.2 (13.4)	
Occupational status			< 0.0001*
Employees	55 (18.2)	50.5 (10.4)	
Unemployed	196 (64.9)	45.3 (9.6)	
Student	51 (16.9)	54.3 (13.2)	

Note: * One-way ANOVA, ** independent t test.

Comparison of total mean QOL scores by socio-demographic characteristics shows that there are no significant differences in total mean QOL scores between groups for socio-demographic characteristics, with the exception of occupational status. Unemployed PWE had a significantly lower total mean QOL score (45.3±9.6) than the PWE who have a professional activity (50.5±10.4) and those of students (54.3±13.2).

3.3 Clinical features of the respondents

One hundred and forty-seven (48.7%) of PWE had had seizures for less than 5 years and 73 (24.2%) had no seizures in the month prior to the survey. Antiepileptic medication was monotherapy in 138 (45.7%) respondents and bitherapy in 33 (10.9%) respondents; 131 (43.4%) had already discontinued antiepileptic therapy. For medical co-morbidity, it was present in 43 (14.2%) participants and the family history of epilepsy was present in 100 (33.1%) respondents. Nicotine dependence was noted in 13 (4.3%) participants and alcohol abuse in 35 (11.6%) participants. Therapeutic adherence was good in only 7 (2.3%) respondents (Table 3).

Table 3 Clinical characteristics of the respondents

Variable	Total (N = 302) n (%)	Total QOL score Mean (SD)	p-value
Duration of epileptic illness			0.241*
< 5 years	147 (48.7)	47.7 (9.3)	
5-10 years	68 (22.5)	46.1 (11.3)	
> 10 years	87 (28.8)	49.1 (13.1)	
Number of seizure attack in the last 30 days			< 0.0001*
0	73 (24.2)	53.7 (13.1)	
1-4	171 (56.6)	46.9 (9.7)	
≥ 5	58 (19.2)	42.5 (8.0)	
Type of seizures			0.065*
Tonico-clonic generalized	230 (76.2)	46.8 (10.5)	
Focal	44 (14.6)	51.2 (13.0)	
Absences	21 (6.9)	49.9 (11.1)	
Unknown	7 (2.3)	50.2 (10.5)	
Antiepileptic medication			0.153*
Monotherapy	138 (45.7)	49.1 (11.1)	
Bitherapy	33 (10.9)	46.7 (12.7)	
None	131 (43.4)	46.6 (10.4)	
Comorbidities			0.003*
Medical	43 (14.2)	44.4 (9.3)	
Psychiatric	37 (12.3)	44.0 (9.6)	
None	222 (73.5)	49.0 (11.3)	
Alcohol consumption			0.316**
No	267 (88.4)	47.9 (11.3)	
Yes	35 (11.6)	46.3 (8.9)	
Smoking			0.029**
No	289 (95.7)	47.9 (11.1)	
Yes	13 (4.3)	43.4 (6.4)	
Family history of epilepsy			0.681**
No	202 (66.9)	47.5 (10.9)	
Yes	100 (33.1)	48.1 (11.3)	

Note: * One-way ANOVA, ** independent t test.

The comparison of total mean QOL scores by clinical characteristics shows that there is no significant difference in total mean QOL scores between groups for the following clinical features: duration of epileptic illness, type of seizures, antiepileptic medication, alcohol consumption, and family history of epilepsy. In contrast, significant differences were noted in the mean total QOL scores between the groups for the following clinical characteristics: number of seizures in the month preceding the survey, co-morbidity and smoking. PWE without seizures had a significantly high mean total QOL score (53.7±13.1) compared to respondents with 1-4 seizures (46.9±9.7), and ≥ 5 seizures (42.5±8.0) ($p < 0.0001$). Respondents with no co-morbidity had a significantly high mean total QOL score (49.0±11.3) compared to those with psychiatric co-morbidity (44.0±9.6), and those with medical co-morbidity (44.4±9.3) (p=0.003). We also noted that the total mean QOL score for PWE who smoked (43.4±6.4) was significantly lower than that for PWE who did not smoke (47.9±11.1) (p=0.029).

3.4 Frequency of seizures and QOLIE-31 score

Correlations between seizure frequency and the total score and subscales of QOLIE-31 are presented in Table 4. All subscales showed a significant correlation with seizure frequency, except for medication effects that showed a non-significant correlation.

Table 4 Correlation between frequency of seizures and total score of QOLIE-31 sub-scales

Subscales of QOLIE-31	Correlation coefficient	p-value
Overall quality of life	-0.08	< 0.0001
Emotional well-being	-0.05	0.014
Energy/fatigue	-0.12	< 0.0001
Cognitive functioning	-0.07	< 0.0001
Seizure worry	-0.03	0.041
Medication effects	-0.005	0.651
Social functioning	-0.05	< 0.0001
Total score	-0.13	< 0.0001

4 Discussion

This study aimed to investigate the QOL of PWE using the QOLIE-31, as QOL has been used to measure health, in addition to morbidity and mortality in patients with epilepsy. It examined the effects of different socio-demographic and clinical factors on QOL in PWE in Goma city in the DRC. QOL is a good health indicator that varies according to different clinical, psychological, and socio-economic variables.

The mean total QOLIE-31 score in our study (47.7±11.0) was lower than in other studies in Togo (49.5±14.4), Benin (52.1±33.4) [15], Malaysia (68.9±15.9) [16], and Australia (52.9±23.1) [17]; it was higher than that recorded in Russia (42.1±4.1) [18]. These differences noted between these studies could be explained by different study methodologies with different inclusion and exclusion criteria but also by differences in socio-cultural or clinical factors.

The lowest mean score was the medication effects subscale with 39.6±27.5 and the lowest was the overall QOL subscale with 57.5±15.0. This finding is significantly different from those noted in other studies. In Australia, the social function sub-scale was the highest and energy/fatigue was the lowest score [17]. In Malaysia [16], Benin, and Togo [15], the authors found that the medication effects sub-scale had the highest score while the seizure worry sub-scale was the lowest. The mean QOL score for the various QOLIE-31 subscales was between 39.7 and 57.5 in our series, which was slightly lower than the study in Saudi Arabia (53.53 to 73.08) [19].

In the present study, PWE's QOL was probably associated with the occupational status. Employees and students had higher scores in QOLIE-31. A similar result was found in the literature [12, 19–22]. A much higher unemployment rate (64.9%) was found among PWE in the present study compared to 58.7%, a rate observed in a Kenyan study [12] which pointed out that more than half (53.4%) of these unemployed blamed their illness (epilepsy) as the cause of their unemployment. For example, it is crucial that adult stabilized PWE actively seek employment in order to achieve a significant improvement in their QOL at the same time.

In this study, the high frequency of seizures had a significant influence on all sub-scales of QOL score except medication effects and seizure worry. Those with frequent seizures had significantly lower QOL score than those with infrequent or controlled seizures. This is in line with the results of other studies proving that seizure frequency is a significant inverse predictor of QOL in different domains [16, 18, 23–25]. As Norsa'adah et al. [16], PWE can take precautions and impose restrictions to prevent seizures from occurring at inappropriate times, in public places or at social gatherings. However, they will still be in the difficult situation of not knowing when the next episode will happen. They may be discouraged from driving and denied career and employment opportunities, which could result in a poorer QOL.

PWE may be concerned about the threat of recurrent seizures, fear of rejection, and social embarrassment. A seizure carries with it a risk of injury, which could also reduce their QOL [16]. Our study also showed that fear of seizures was significantly associated with the frequency of seizures. This could be explained by the fact that many PWE still feel powerless and lack confidence even when seizures are under control, which has a negative influence on their QOL.

Indeed, as everywhere else and at all times, the image of the "excluded epileptic" was recognized and found in several expressions meaning the disease that causes it to fall [26]. As a result, in Africa, a PWE was viewed strangely by those around him or her as dangerous, violent, insane, or contagious. These characteristics lead to a temporary disability and a more or less significant change in QOL [27].

5 Limitation

A major limitation is that a self-administered questionnaire (QOLIE-31) was used to collect QOL information but had not been translated into the national Kiswahili language. Despite the fact that none of the subjects reported problems with understanding the QOLIE-31, a translation would have facilitated their interpretation to capture more subjectivity.

6 Conclusion

Several social and clinical factors have a significant impact on QOL. Therefore, screening for psychiatric co-morbidities is essential to improve QOL in such PWE. In addition to clinical counseling, addressing psychosocial and emotional aspects is a key to improving the PWE's QOL. Public awareness and education campaigns will reduce the impact of mistaken beliefs and practices harmful to PWE.

List of abbreviations

95% CI: 95% confidence interval
DRC: Democratic Republic of the Congo
PWE: people with epilepsy
QOL: quality of life
QOLIE-31: Quality of Life in Epilepsy-31 inventory
SD: standard deviation
SSA: Sub-Saharan Africa
WHO: World Health Organization

Data Availability

The datasheet used to support the findings of this study are available from the corresponding author (OM) upon request.

Competing interests

The authors declare that they have no competing interests.

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