

Quality of life in people with epilepsy and their family caregivers

An Arab experience using the short version of the World Health Organization quality of life instrument

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ABSTRACT

الأهداف: تقييم جودة الحياة (QOL) في مرضى سودانيين يعانون من نوبات صرع كبرى ومقدمي الرعاية من ذويهم ب ومقارنتهم مع الأشخاص العاديين وكذلك بيانات سابقة عن مرضى سودانيين يعانون من أمراض مزمنة أخرى وفحص العوامل التي تحدد جودة الحياة QOL.

الطريقة: أجريت دراسة مقطعية باستخدام مقياس منظمة الصحة العالمية لجودة الحياة والذي يحتوي على 26 سؤال. اشتملت هذه الدراسة على المرضى ومقدمي الرعاية من ذويهم ممن ترددوا على عيادة الأعصاب وتطبيق عليهم شروط البحث بتصميم دراسة عرضية بالمستشفى الحكومي خلال الفترة من ديسمبر 2005 إلى ديسمبر 2006 - مدينة الخرطوم - وادي مدني وعتبرة - السودان.

النتائج: خلصت النتائج إلى وجود 276 مريض (56.5% ذكر، وكان متوسط العمر 29.5 عام). وقد أظهرت النتائج انخفاض في مقياس جودة الحياة QOL لدى المرضى مقارنة مع المجموعة الضابطة وكان هذا الاختلاف ذو دلالة إحصائية (57.1% في الصحة الجسدية، 60.1% في المقياس النفسي، 58.4% في العلاقات الاجتماعية، 50.6% في البيئة، و 60.8% في جودة الحياة عموماً). وقد أشارت النتائج إلى انخفاض تلك القيم مقارنة بالمرضى في 23 دولة خاصة في العلاقات الاجتماعية والنواحي البيئية وكذلك في النواحي البيئية في المرضى السودانيين الذين يعانون من مرض السكري. وكانت الدرجات مرتفعة في مقدمي الرعاية لهؤلاء المرضى (57.4-73.7%) مقارنة بالمرضى والمجموعة الضابطة. كما خلصت النتائج إلى أن ارتفاع الأداء لدى المرضى على مقياس جودة الحياة QOL مرتبط بالزواج والتعليم والوظيفة وعدم وجود آثار جانبية للأدوية وكذلك عمل مقدمي الرعاية. أما مقدمي الرعاية للمرضى فكان منخفض القيم على مقياس جودة الحياة QOL مرتبط ببعض العوامل مثل أن يكون مقدمي الرعاية من الإناث أو إذا كان للمريض أبناء أو أقل تعليماً. وقد استندت العوامل التي تحدد جودة الحياة QOL على وجهة نظر مقدمي الرعاية تجاه المرضى والآثار الجانبية للأدوية.

خاتمة: فقر جودة الحياة QOL لدى مرضى الصرع يشير إلى إنجاز أقل في المجتمع، ويتطلب برامج لتحسين الظروف الاجتماعية والنفسية والخدمات الصحية. أما مقدمي الرعاية المعرضين لأداء منخفض في جودة الحياة QOL فإنهم يحتاجون المساعدة لتدعيم دورهم.

Objectives: To assess the subjective quality of life (QOL) of Sudanese epilepsy patients with generalized tonic clonic seizures and their family caregivers, compared with the general population, and previous Sudanese data for chronic conditions, and to examine the predictors of QOL.

Methods: This cross-sectional study using the World Health Organization's 26-item QOL instrument, was carried out from December 2005 to December 2006, on consecutive government hospital Neurology Clinic attendees and their family caregivers, who fulfilled the study's inclusion criteria, in the cities of Khartoum, Wad Medani, and Atbara, Sudan.

Results: There were 276 patients (56.5% male; mean age 29.5 years). Patients' QOL scores were significantly lower (physical health domain [57.1%], psychological [60.1%], social relations [58.4%], environment [50.6%], and general facet [60.8%]), than the control group. They scored lower than the WHO 23-country patients for social relations and environment domains, and had lower environment domain scores than Sudanese diabetes patients. Caregivers had significantly higher scores (57.4-73.7%) than patients and control group. Patients' higher QOL was associated with marriage, education, employment, no side effects and caregiver occupation. Caregivers had lower QOL if they were female, patients' own children, and less educated. The predictors of QOL included caregiver's proxy rating of the patient's QOL and drug side effects.

Conclusion: Poor QOL in epilepsy reflects social underachievement, and calls for programs to remedy their psychosocial circumstance, and improve service provisions. Vulnerable caregivers need to be identified for assistance, to enhance their role.

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Epilepsy is a multifaceted chronic disorder, which has diverse effects on the overall well being or subjective quality of life (QOL) of the patients.^{1,2} In the past decade, there has been a lot of interest in the factors associated with QOL in epilepsy.²⁻⁷ This line of inquiry is useful because QOL is sensitive to distress in several domains of living,⁸ hence, a focus on its determinants can help to narrow down the domains, in which interventions can be targeted to improve outcome and quality of care.^{6,9} A better understanding of how satisfied people living with epilepsy are with their lives is necessary for clinicians to help the patients lead more fulfilling lives.^{3,4} A consistent finding from these studies is that QOL in epilepsy is associated with several factors. These factors include clinical variables (for example, seizure frequency, severity, illness duration, treatment side effects, and psychiatric co-morbidity), social disadvantage (for example, divorce, unemployment, social stigma, and illness intrusion into social life), and family circumstances (such as, family caregiver characteristics, and social support).^{1-5,10} An area that has received scant attention among these factors in the literature is the QOL of family caregivers of people with epilepsy,^{5,11,12} and the impact of caregivers' impression (or proxy rating) of the patients' QOL.^{7,11} This apparent lack of research interest is surprising because, for such a chronic illness that starts early in life and is associated with social under achievement,^{1,13} the burden on family caregivers is enormous.¹⁴ Accordingly, caregivers of people with epilepsy are at high risk for anxiety, and caregivers' anxiety is significantly correlated with the patients' QOL.^{12,15,16} Research on caregiver proxy rating of patient's QOL (namely, caregiver impression of the patient's QOL)^{7,11,17} is important for the following reasons. First, the psychological literature on "expressed emotions" (namely, the impact of emotional interactions in the family on clinical outcome) has shown that the family caregiver's positive appraisal of the patient has a positive impact on patient's clinical outcome.¹⁸ Second, Sneeuw et al¹⁹ had suggested that in chronic conditions that are associated with cognitive impairment, as consistently shown in epilepsy by their educational underachievement,^{1,13,14} there is need to assess family caregivers for their views on the patients' QOL. Third, recent reports have indicated that family caregiver's impression of the patient's QOL is a significant predictor of the overall QOL of that of the patient and that of the caregiver, for psychiatric and diabetes mellitus (DM) populations.^{20,21} Hence, it is important to see whether the results will be confirmed in a population of epilepsy persons with generalized tonic clonic seizures. These issues are of interest in the Arab world, because a few psychosocial studies on epilepsy showed that rates of anxiety and depression are higher among people

with epilepsy,²² and that adverse effects on education, marriage, and occupation are common.^{23,24} There is a paucity of reports on the QOL of persons with epilepsy from the Arab world.² Based on the literature, the conceptual framework for our study is that the QOL of persons with epilepsy and their family caregivers is lower than that of the general population and other chronic illness groups, and would be predicted by socio-demographic characteristics, duration of illness, drug side effects, and the caregivers' proxy rating of the patients' QOL.^{10,20,21} The objectives of the study were: to assess the subjective QOL of Sudanese subjects currently receiving drug treatment for epilepsy with generalized tonic clonic seizure, in stable clinical condition, along with their family caregivers, in comparison with socio-demographically matched general population samples, using the World Health Organization (26 items) QOL instrument (the WHOQOL-Bref);²⁵ to compare the patients' data with the WHO 23-country data for sick persons,²⁵ as well as data of patients with mental disorders and DM who were similarly assessed in previous studies in Sudan;^{21,26} to assess the association of patients' QOL domain scores with socio-demographic variables, duration of illness, and treatment side effects; to examine the concordance between the patients' ratings and family caregivers' proxy ratings of the patients' QOL (referred to as caregivers' impression of the patients' QOL);^{7,11,19} to assess the predictors of patients' and caregivers' QOL. We hypothesized that epilepsy patients currently receiving drug treatment and their caregivers would have significantly lower QOL than the control groups and corresponding WHO data.^{1-3,25} Furthermore, the most significant predictor of the patients' and caregivers' QOL would be the caregivers' impression of the patients' QOL.^{20,21}

Methods. Sudan is a north-eastern African country (population: 39,379,358 by 2007 estimate) with predominantly Arab population. The patients were seen at the outpatient clinics of the Medicine and Psychiatric Departments of the government hospitals in Metropolitan Khartoum, Wad Medani Teaching Hospital in central Sudan, and Atbara Teaching Hospital in northern Sudan. These are fee-for-service clinics. The available report on the burden of epilepsy in Sudan indicated that among school pupils in Khartoum, the prevalence of epilepsy is 0.9 per 1000.²⁷ According to the statistics in 2007 from the Federal Ministry of Health, Khartoum, Sudan, 8269 persons (male: 4456, female: 3813) attended the outpatient clinics for epilepsy in the country. A review of epidemiological studies on epilepsy in Arab countries found that the prevalence ranged from 0.91/1000 in Sudan to 6.54/1000 in Saudi Arabia, with a median of 2.3/1000, and a higher prevalence among

males, children, and young adults.²⁸ Most cases had primary generalized seizures (28-97%), and idiopathic epilepsy (73.5-82.6%).

The patients were consecutive clinic attendees who were currently receiving follow-up drug treatment. None had undergone surgery for epilepsy. In order to ensure the inclusion of those with sufficient experience of the illness, and who could participate reliably in the research interview, the inclusion criteria were: above 15 years of age, a case-note diagnosis of epilepsy with generalized tonic clonic seizures for at least one year, experience of at least one seizure in the past year, and attending clinic for routine follow-up. All the patients were in stable clinical condition at the time of assessment. The exclusion criteria were: impairment of consciousness, mental retardation, and speech impairment. Each patient was accompanied by at least one family member who lived with him/her, and was predominantly responsible for caring for the patient at home. In the traditional extended family system, care-giving roles are shared by several people in the household.²⁰ The general population groups were selected by quota sampling from a WHOQOL-Bref database for Sudan,²⁶ to match patient and caregiver groups socio-demographically. The WHOQOL-Bref is a 26-item self-administered generic QOL questionnaire, a short version of the WHOQOL-100 instrument.²⁵ It is made up of domains and facets. Domains are broad groupings of related facets. Higher domain/facet scores indicate better QOL. The items on "overall rating of QOL" and satisfaction with general health are not included in the domains, but constitute the "general facet on health and QOL". The remaining 24 items constitute 4 domains, namely, physical health (7 items), psychological health (6 items), social relations (3 items), and environment (8 items). The domain scores can be derived in 3 ways.²⁹ The first is a summation of the raw scores of the constituent items. In the second way, the raw scores are transformed to range from 4-20, equivalent to the corresponding WHOQOL-100 domains. The third way, which is the percentage scale maximum (%SM) is a standardized conversion of Likert-scale data projected on to a 0-100 scale. The importance of the %SM measure is that it can be used for making comparison with other scales.³⁰ The WHO has provided an international data for the WHOQOL-Bref from a study of 23 countries, including developing and developed countries.²⁵ We present data for the transformed domain scores (namely, 4-20 and 0-100%). The WHOQOL-Bref was of interest to our study for the following reasons: first, it was simultaneously developed in cultures from all regions of the world, thus overcoming the usual controversy over the application of a questionnaire articulated in one culture in a different culture.³¹ Second, it is fairly comprehensive,

encompassing health-related QOL aspects (physical health and psychological domains), contextual issues (social relations and environment domains), and general subjective well being (general facet on health, and QOL).³² Third, the Arabic translation of the WHOQOL-Bref has been shown to have significant validity and reliability indices in Sudan.³³ We accepted the WHO definition of QOL as individuals' perception of life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns.²⁵ Our focus was on subjective QOL, as distinct from objective QOL.²⁶ In order to produce the version of the WHOQOL-Bref with which the family caregivers rated their impression of the patients' QOL, we used the method of Sainfort et al,¹⁷ by giving a new direction to each item, so that the caregiver could rate the patient as the patient would rate him/herself. This is the "proxy-patient" method (namely, the proxy's assessment from the patient's perspective),³⁴ which was used in previous Sudanese studies.^{20,21,26} The internal consistency of the WHOQOL-Bref, as assessed by Cronbach's alpha coefficient for the responses of all subjects, was highly significant (>0.86) for patients, caregivers, and caregiver proxy ratings. The questionnaires were translated into Arabic by the method of back-translation, and have been used in studies in Sudan.^{20,21} Ethical approval for the study was obtained from the Sudan University of Science and Technology, Khartoum, and authorities of the hospitals. The patients and their family caregivers gave verbal informed consent to participate. Subjects were assessed in 2005-2006. The patients and their caregivers self-completed the questionnaires under the supervision of trained female research assistants (RAs). At the preliminary stage of the study, the RAs were trained in the use of the questionnaires. Most patients and caregivers completed the questionnaires privately and independently, after clarification of the meaning of the items. Literacy rate in Arabic language is very high in Sudan. In order to minimize interference by the staff and ensure reliability of responses, a few illiterate patients were assisted by their educated relatives to complete the questionnaire, after the caregiver had completed his/her own. As recommended by the WHOQOL group,^{25,29} the illiterate caregivers had the questionnaires read out to them by the RAs. No formal inter-rater reliability tests were carried out because the vast majority of questionnaires were self-rated. However, one of the investigators held meetings with the RAs during the course of the study to ensure that they were following correct procedures. The physician in-charge of each case assisted the RAs to record relevant clinical data.

Data were analyzed by the Statistical Package for Social Sciences version 11 (SPSS Inc., Chicago, IL,

USA). The QOL scores were generated by organizing the items of the WHOQOL-Bref into domains. The domain scores for the patients and caregivers were compared with those of the respective general population control groups by t-test, and effect size calculations. For the international perspective, domain scores of patients were compared with those of WHO normative data for sick persons, using the 4-20 transformed scores, corrected (by analysis of covariance [ANCOVA]) for socio-demographic variables.²⁵ Similarly, domain scores were compared with those patients with psychiatric disorders and DM, who had been assessed in Sudan in previous studies.^{21,26} For this analysis, the scores were adjusted (by ANCOVA) for age, gender, and duration of illness. We used Pearson's correlation, chi-square tests, one-way analysis of variance (ANOVA) and ANCOVA, to assess the socio-demographic and clinical variables associated with QOL. The concordance between patient's WHOQOL-Bref rating and the caregiver proxy rating of the patient was assessed by Kendall's tau and intra-class correlation (ICC).¹⁹ We preferred the more conservative Kendall's tau (over Pearson's correlation) because it takes ties into consideration. The predictors of patients' QOL and caregivers' QOL (namely, patients' general facet and caregivers' general facet as dependent variables) were assessed in step-wise regression analyses. Based on previous results,^{20,21} the regression analysis was carried out by entering the variables in blocks, starting with the socio-demographic and clinical variables, followed by the caregiver's proxy rating of the patient's QOL. A Bonferroni correction ($p=0.01$) was applied for multiple tests, otherwise, the level of statistical significance was set at $p<0.05$.

Results. The patient's mean duration of illness was 10.7 years. They were predominantly young (84.4% were aged ≤ 40 years, mean \pm SD; 29.5 ± 11.7 , range 15-75). Most of the patients were single, and with less than high school education. They were exactly matched with their control group for gender and age, but the control group was better educated ($p=0.001$). Most caregivers were women, married, either unemployed (42%), or in low-skilled occupations (25.7%), and had some secondary school education. Most caregivers (66.2%) were either parents or siblings, and 15.2% were either spouses, or own children of the patients. They were well-matched with their control group for gender, age and education. (Table 1). Using %SM, the patients' QOL domain scores were rather low (range 50.6-60.8%) (Table 2). In all domains, the patients had significantly lower scores than their control group (t ranged from 2.8-4.6, $p=0.0001$). The magnitude of effect size ranged from small (0.21) to medium (0.74). The caregivers had fairly high QOL scores, except in the environment domain. The caregivers had significantly higher scores than their control group (t ranged from 2.6-4.5, $p=0.001$), and patients (paired t ranged from 4.4-13.7, $p=0.0001$). Caregivers who were children of the patients had significantly lowest scores for most domains ($p=0.0001$). In assessing the association of socio-demographic variables with QOL for the patients, there were no significant gender differences in QOL domain scores ($p>0.05$). In ANCOVA, the significant covariates were as follows: a) patients' age was negatively correlated with their QOL ($F = -3.9$ to -6.1 , $p=0.02$), b) higher QOL scores for patients were associated with patient being married and engaged in high-skilled

Table 1 - Socio-demographic characteristics of patients and family caregivers.

Variables	Epilepsy patients N=276	Control group N=275	P-value	Caregivers N=257	Control group for caregivers N=248	P-value
<i>Gender, n (%)</i>			>0.05			>0.05
Male	156 (56.5)	155 (56.4)		119 (46.3)	117 (47.2)	
Female	120 (43.5)	120 (43.6)		138 (53.7)	131 (52.8)	
Age (standard deviation)	29.5 (11.7)	29.6 (11.5)	>0.05	38.2 (12.3)	38.2 (12.2)	>0.05
<i>Marital status, n (%)</i>		-	-		-	-
Single	183 (66.3)			79 (31.2)		
Married	69 (25.0)			154 (60.5)		
<i>Employment status, n (%)</i>		-	-		-	-
Unemployed	111 (40.2)			108 (42)		
Student	128 (46.4)			95 (37.0)		
Medium and high skill	34 (12.3)			54 (21.0)		
<i>Education, n (%)</i>			-			
Primary school	158 (57.2)	81 (29.5)		112 (43.9)	98 (39.5)	
High school	118 (42.7)	194 (70.5)	0.001	143 (56.1)	150 (60.5)	>0.05
College						
Duration of illness (years)	10.7 (9.3)	-	-	-	-	-

occupation ($F = 4.4-10.1$, $p=0.02$), as well as caregiver being married and engaged in high-skilled occupation ($F = 3.9-7.3$, $p=0.02$). In the case of the family caregivers, we found that the patients' socio-demographic variables had no significant association with the caregivers' QOL domains scores. In ANCOVA, higher QOL for caregivers was significantly associated with being male and better educated ($F = 10.2$, $p=0.002$). In assessing the association of clinical variables with QOL, we found that the correlations between the duration of illness and QOL were negative for all domains, but not significant. Also, there was no significant correlation between the patients' duration of illness and epilepsy caregivers' QOL ($p>0.05$). However, the patient's duration of illness was significantly correlated with the caregiver rating the patient as having better QOL

($r = 0.27 - 0.60$, $p=0.001$). In the case of treatment side effects, patients with gum hyperplasia and skin rash had significantly lower QOL for psychological health ($t = 2.6$, $p=0.009$), and social relations ($t = 2.5$, $p=0.01$) domains. Patients with ataxia, diplopia, and tremors had significantly lower QOL for most domains ($t = 2.1 - 3.9$, $p<0.006$ mostly), except environment ($p>0.05$). In assessing the concordance of patients' and caregivers' proxy ratings, we found that the patients' ratings of their QOL and caregivers' proxy scores were significantly correlated (Kendall's tau mostly $0.33 - 0.57$, $p=0.001$). Furthermore, there was significant internal consistency between patients' ratings and caregivers' proxy ratings (intra-class correlation = 0.94 ; 95% confidence interval (CI) = $0.92-0.95$). In the stepwise regression analyses (Table 3), the significant variables accounted for only

Table 2 - Differences in QOL domain scores for patients, family caregivers, and general population control groups.*

QOL domains	Epilepsy (N=273) Mean (standard deviation)		Control group (N=257) Mean (standard deviation)		Standardized effect size calculations using 4-20 scores
<i>Patients[†]</i>	4-20 (1)	0-100%	4-20 (2)	0-100%	(95% confidence interval)
Physical health	13.1 (2.8)	57.1 (17.4)	15.2 (2.9)	69.8 (17.9)	0.74 (0.56-0.91)
Psychological health	13.6 (3.1)	60.1 (19.5)	14.6 (2.9)	66.5 (17.9)	0.33 (0.16-0.50)
Social relations	13.3 (4.2)	58.4 (26.1)	14.9 (3.3)	67.9 (20.6)	0.42 (0.25-0.59)
Environment	12.0 (3.0)	50.6 (18.9)	12.6 (2.8)	53.5 (17.5)	0.21 (0.04-0.38)
General facet	13.7 (3.8)	60.8 (23.6)	14.7 (3.8)	66.9 (23.9)	0.26 (0.09-0.43)
<i>Family caregivers[†]</i>	N=254		N=232		
Physical health	15.8 (2.5)	73.7 (15.9)	14.9 (2.7)	68.3 (17.0)	0.35 (0.17-0.53)
Psychological health	15.6 (2.2)	72.7 (13.5)	14.6 (2.7)	66.4 (16.9)	0.41 (0.23-0.59)
Social relations	15.6 (3.2)	72.3 (19.9)	14.7 (3.2)	67.3 (19.9)	0.28 (0.10-0.46)
Environment	13.2 (2.6)	57.4 (16.3)	12.5 (2.9)	52.8 (18.1)	0.25 (0.08-0.43)
General facet	15.9 (3.0)	74.8 (18.8)	14.3 (3.7)	64.4 (23.1)	0.48 (0.30-0.66)

*In all domains and the general facet, higher scores indicate better quality of life (QOL)

[†]In all domains, caregivers had significantly higher scores than patients (paired t : $4.4-13.7$, $p<0.001$)

Table 3 - Predictors of quality of life (QOL) of patients and caregivers with their general facet on health and QOL as dependent variables in step-wise regression analyses.*

Dependent variable	Predictors or independent variables	Variance (%)	Total variance (%)	Beta	t test	P-value
General facet on health and QOL for epilepsy patients	General facet caregiver's proxy rating of patient's QOL	10.0	14.5	0.32	5.2	0.000
	Occupation of patient	2.4		0.12	1.9	0.05
	CNS side effects	2.1		0.09	1.6	0.12
General facet on health and QOL for carers of epilepsy patients	Caregiver currently feels not ill	13.2	17.2	0.34	5.7	0.000
	Caregivers education	2.4		0.15	2.5	0.01
	General facet caregiver's proxy rating of patient's QOL	1.5		0.15	2.1	0.03

*The independent variables were: patient and caregiver socio-demographic characteristics, patient and caregiver self-rated illness, sexual/other side effects of treatment, general facet caregiver's proxy rating of patient's QOL, duration of illness.

14.5-17.2% of variance. The most important predictor of the patients' QOL was the general facet derived from the family caregivers' proxy rating of the patients' QOL. Patients' occupation, and CNS side effects played relatively minor roles.

Discussion. According to the socio-demographic characteristics in this study, the patients were predominantly young, less educated, less likely to be married, more unemployed, and ill for several years. This was in line with the expectations from the literature.¹³ Accordingly, most caregivers were parents. These characteristics indicate that our subjects were typical of the clinical samples reported for QOL studies in epilepsy.^{2,6,10} The higher proportion of males and younger age groups indicate that our patients had similar characteristics with the general population of epilepsy patients reported in the epidemiological studies from Arab countries.²⁸

We analyzed our QOL data in such a way as to make them comparable with the WHO 23-country data, which included results for subjects from both developing and developed countries.²⁵ Using scores adjusted for age and gender, our patients had similar scores with the WHO data for sick persons, for physical health (13.1 each) and psychological (13.6 versus 13.7) domains, but had lesser scores than the WHO data for social relations (13.4 versus 14.0), and environment (12.1 versus 13.8) domains (the tests of significance difference could not be carried out because the total number of patients for WHO data was not provided in the report). Also, the tendency for Sudanese diabetic patients (N=243) assessed in a previous study²¹ to have higher scores than our patients, for the general facet, physical health, psychological, and social relations domains did not reach significance ($p > 0.05$). However, diabetic patients had significantly higher scores for the environment domain (effect size [ES]: 95% CI; 0.36: 0.18-0.53). Our epilepsy patients had significantly higher scores than the Sudanese psychiatric patients (N=299)²⁶ for the general facet, physical health, psychological, and social relations domains (ES: 0.20-0.78). These results are similar to a USA study of epilepsy, which included DM and multiple sclerosis patients.³⁵ We suggest that the rather poor QOL in epilepsy (50.6-60.8%) could be accounted for by the group's disease chronicity (mean duration of illness; 10.7 years), their social under-achievement, the noted impact of life-long social stigma,^{1,36} and possibly, the absence of fee-subsidy services, and consequent unmet need for care.³⁷ We speculate that caregivers' higher QOL is possibly related to their positive psychological response to the challenge of care giving,^{20,38} as described in the

studies on the phenomenon of benefit finding (namely, the human capacity to find positive meaning in adverse circumstances).^{39,40} Benefit finding has been linked with life satisfaction and coping among caregivers.^{39,40} Although we did not assess the phenomenon of benefit finding, this idea is quite familiar in the religious culture in Sudan. Our findings call for improved provision of services, and for the clinician to consider that protracted years of seizure and social stigma can render the patient vulnerable to diminished functional living.³⁶

The following findings for socio-demographic and clinical correlates of QOL are noteworthy: first, higher QOL was significantly associated with younger age, being married, higher educational attainments and higher levels of employment.^{2,41} It is reasonable to suggest that these factors increase the potential for awareness of the disease, social support, and the use of positive coping methods. Second, our data indicate that families living with epilepsy patients are vulnerable to diminished QOL if the caregiver is female, older, less educated, and unemployed.⁴² Such patient-caregiver dyads need to be singled out for relevant social support by the clinical team. Third, the high degree of concordance of the patient-caregiver ratings is in line with the literature.^{11,19} This supports the reliability of the responses of the patients, and shows that these caregivers shared the experience of the patients, and exhibited a sensitive empathy, or "social intelligence."⁴³ Finally, we examined the predictors of patients' and caregivers' QOL. In this regard, the finding that caregivers' proxy rating of the patients' QOL was a significant predictor of the QOL of the patients and the QOL of caregivers has been replicated in studies of multiple sclerosis, psychiatric, and diabetic populations, and therefore merits attention.^{20,21,44,45} In the case of patients, it is possible to explain this finding from the perspective of high concordance of the patient-caregiver ratings. However, this finding is in line with "expressed emotions" research in psychology,¹⁸ as well as reports indicating that patient-caregiver characteristics do impact each other's QOL.^{12,15}

To account for the predictive power of caregiver's proxy rating, we speculate that recent brain-behavior findings on "mirror neurons"⁴⁶ and the phenomenon of "social intelligence" indicate that the patient-caregiver dyad interaction, and its impact on QOL has roots in the neurology of human behavior.^{43,46} Furthermore, recent reports on positive emotions have shown that happiness can spread from person to person within social networks, such that people's happiness depends on the happiness of others with whom they are connected, especially co-resident family members.⁴⁷

The other significant predictor of caregiver QOL (namely, the caregiver self-rated state of health), is an often neglected index of family vulnerability in clinical practice.⁴⁸ This implies that caregiving ability should not be taken for granted.

The major limitations of the study are; it was cross-sectional, we did not assess seizure frequency, co-morbidity, and disease severity, and we did not record drug treatments. However, we compared an epilepsy group and their family caregivers with matched general population control groups. We also compared our results with previous Sudanese data for patients with mental disorders and DM, as well as the WHO 23-country data for sick persons. Finally, we obtained caregiver proxy ratings of the patients.

In conclusion, poor QOL in epilepsy reflects the impact of side effects of treatment, illness chronicity and social underachievement. These call for attention to treatment side effects and therapeutic optimism on the part of clinicians, and programs to improve the patients' psychosocial circumstance. There is need for specific health service provisions for those with social disadvantage, since user fees are a known barrier to accessing health care, and service satisfaction is significantly associated with QOL.³⁷ Vulnerable caregivers need to be identified for assistance to improve their caregiving ability. The predictive power of the caregivers' impression of patients' QOL shows that clinicians need to invest in the education and social support of family caregivers. Future studies should incorporate the above factors in interventions for improving the QOL of persons with epilepsy and their family caregivers.

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