

Quality of life in people with epilepsy and their family caregivers: An Arab experience using the short version of WHO Quality of Life Instrument

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Quality of life in people with epilepsy and their family caregivers: an Arab experience using the WHOQOL-Bref

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**Abstract**

*Purpose:* To assess the subjective quality of life (QOL) of Sudanese epilepsy patients with grand-mal seizures and their family caregivers, using the WHO 26-item QOL Instrument, compared with the general population and previous data; and examine the predictors of QOL. *Methods:* Consecutive clinic attendees (N = 276) and their family caregivers were assessed in north and central Sudan. *Results:* Patients' QOL scores were rather poor (50.6 -60.8%), and significantly lower than their control group. They scored lower than WHO patients for social relations and environment domains, and also had lower environment domain scores than Sudanese diabetes patients. Caregivers had significantly higher scores(57.4 -73.7%) than patients and control group. There was significant concordance between patient's rating and caregiver's rating of patient. 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 child, and less educated. The predictors of QOL included caregiver's proxy rating of the patient's QOL and drug side effects. *Conclusions:* Poor QOL in epilepsy reflects social underachievement and calls for programs to remedy their psychosocial circumstance and improve health service provisions. Vulnerable caregivers need to be identified for assistance to enhance their role.

## **Introduction**

Epilepsy is a multifaceted chronic disorder which has diverse and complex effects on the overall wellbeing or subjective quality of life (QOL) of the patients [1,2]. In recent times, 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], and 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 if clinicians are to better help the patients lead more fulfilling lives.

The most consistent pattern that has emerged from these inquiries is that QOL in epilepsy is a function of the interaction of factors, which include: clinical variables (e.g., seizure frequency, severity, illness duration, treatment side effects, psychiatric co-morbidity), social disadvantage (e.g., divorce, unemployment, social stigma, illness intrusion into social life), and family circumstances (e.g., family caregiver characteristics, 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 underachievement [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 patients' QOL [12,15,16]. Research on caregiver proxy rating of patient's QOL (i.e., caregiver impression of the patient's QOL) [7,11,17] is important for the following reasons. First,

the psychological literature on “expressed emotions” (i.e., the impact of emotional interactions in the family on clinical outcome) has consistently shown that family caregiver’s positive appraisal of the patient has a positive impact on patient’s clinical outcome [18]. Second, Sneeuw et. al [19] have 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 populations[20,21]. Hence, it is important to see whether the results will be replicated in a population of epilepsy persons with grand - mal seizures.

These issues are of interest in the Arab world because the few psychosocial studies on epilepsy showed that rates of anxiety and depression are higher among people with epilepsy [22], and 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 was 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].

*Objectives:*

The objectives of the study were:

- to assess the subjective QOL of Sudanese subjects currently receiving drug treatment for epilepsy with grand-mal seizures, in stable clinical condition, along with their family caregivers, in comparison with socio-demographically matched general population samples, using the WHO 26 - item Quality of Life Instrument ( the WHOQOL - Bref);
- 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 diabetes mellitus 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 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**

### *The setting:*

Sudan is a northeastern African country (population: 39,379,358 by 2007 estimate) with predominantly Arab population. The patients were seen at the outpatient clinics of medicine and psychiatric departments of the government hospitals in: (i) Metropolitan Khartoum; (ii) Wad Medani teaching hospital in central Sudan; and (iii) 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 the capital, Khartoum, the prevalence of epilepsy is 0.9 per 1000 [27]. However, a report from the region, based on probability samples of adults, indicated that the prevalence of epilepsy is about 6.54/1000 population in Saudi Arabia [28].

*Subjects:*

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 research interview, the inclusion criteria were: age above 15 years, a formal diagnosis of epilepsy with grand-mal 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 (i.e., they were fully conscious, could participate in research interview, and had no need for increase in medication dosage). 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 where the patients lived, care giving roles are shared by several people in the household [20]. Family care giving is a voluntary, life-long, responsibility for which there are no material inducements. The general population groups were selected by quota sampling from our WHOQOL-Bref data base for Sudan [26], to match patient and caregiver groups by sex, age, and level of education.

*The WHOQOL – Bref*

This is a 26 –item self –administered generic 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 four domains, namely, physical health (7 items), psychological health (6 items), social relations (3 items) and environment (eight items). The domain scores can be derived in three 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 to 20, equivalent to the corresponding WHOQOL-100 domain. 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 value of the %SM measure is that it can be used for making comparison with other scales [30]. The WHO has provided 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 (i.e., 4 - 20 & 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 “emics” and “etics” of applying 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 wellbeing (general facet on health & QOL) [32]. Third, the Arabic

translation of the WHOQOL-Bref has been shown to have highly 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].

*Caregiver proxy ratings:*

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 (i.e., 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 very high ( $> 0.86$ ) for patients, caregivers and caregiver proxy rating.

*Data collection:*

The questionnaires were translated into Arabic by the method of back – translation and have been used in recent 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 completed the questionnaires under the supervision of trained research

assistants (female social welfare staff of the respective clinics). At the preliminary stage of the study, the research assistants (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 because it is the language of the Holy Koran. In order to minimize interference by staff and ensure reliability of responses, the 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 done 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 research assistants to record the relevant clinical data.

*Data analysis:*

Data were analyzed by the SPSS - version 11 (SPSS Inc Chicago, Illinois). 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 for socio-demographic variables [25]. Similarly, domain scores were compared with those of patients with psychiatric disorders and diabetes mellitus, who had been assessed in Sudan in previous studies [21,26]. For this exercise, the scores were adjusted for age, sex and duration of

illness. We used Pearson's correlation, chi-square tests, one-way ANOVA, and analysis of covariance (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 (i.e., 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 done 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. All tests were two-tailed. A Bonferroni correction ( $P = 0.01$ ) was applied for multiple tests; otherwise, the level of statistical significance was set at  $P < 0.05$ .

## **Results**

### *Socio-demographic characteristics (Table 1):*

There were 276 epilepsy patients with grand-mal seizures (56.5% men), and their mean duration of illness was 10.7(9.3) years. They were predominantly young (84.4% were aged  $\leq 40$  yrs, mean 29.5 yrs, range 15 -75). Majority were single (66.5%), and with less than high school education (57.3%). They were exactly matched with their control group for sex and age, but the control group was better educated ( $P < 0.001$ ). The 257 family caregivers were aged 38.2 (SD 12.3) years. Majority of caregivers were women (53.7%), married (60.9%), either unemployed (42.0%) or in low skilled occupation (25.7%), and had some secondary school education (56.1%). 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 (N = 248) for gender, age and education.

*Differences in QOL (Table 2):*

Using %SM, the patients' QOL domain scores were rather low (range 50.6% - 60.8%). In all domains, the patients had significantly lower scores than their control group (t ranged from 2.8 to 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 (72.3% - 74.8%), except in the environment domain (57.4%). The caregivers had significantly higher scores than their control group (t ranged from 2.6 to 4.5,  $P < 0.001$ ) and patients (paired t ranged from 4.4 to 13.7,  $P < 0.0001$ ). Caregivers who were children of the patients had significantly lowest scores for most domains ( $P < 0.0001$ ).

*Association of socio-demographic variables with QOL*

*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 occupation ( $F = 4.4$  to  $10.1$ ,  $P < 0.02$ ), as well as caregiver being married and engaged in high skilled occupation ( $F = 3.9$  to  $7.3$ ,  $P < 0.02$ ).

*Family caregivers:*

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 ( $F = 10.2$ ,  $P < 0.002$ ).

*Clinical variables and QOL:*

*Duration of illness:*

Correlations between duration of illness and QOL were negative for all domains, but not significant. Also, there was no significant correlation between patients' duration of illness and epilepsy caregivers' QOL ( $P > 0.05$ ). However, patient's duration of illness was significantly correlated with caregiver rating the patient as having higher QOL ( $r = 0.27$  to  $0.60$ ,  $P < 0.001$ ).

*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 ( $t = 2.1$  to  $3.9$ ,  $P$  mostly  $< 0.006$ ), except environment ( $P > 0.05$ ).

*Concordance of patients' and caregivers' proxy ratings*

Patients' ratings of their QOL and caregivers' proxy scores were highly 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% C.I. =  $0.92 - 0.95$ ).

*Predictors of QOL (Table 3)*

In stepwise regression analyses, 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 (2.4% of variance) and CNS side effects (2.1%) played relatively minor roles. For the family caregivers' QOL, the general facet derived from the caregivers' proxy rating accounted for 1.5% of the variance, while caregivers' self-rated

current state of health and education accounted for 13.2% and 2.4% of the variance, respectively.

### **Discussion:**

*Limitations and strengths:* The study was cross-sectional, we did not assess seizure frequency and disease severity and we did not record the drug treatments. However, we compared an epilepsy group and their family caregivers with matched general population control groups. We shall also compare our results with previous Sudanese data for patients with mental disorders and diabetes mellitus, as well as the WHO 23 –country data for sick persons. Finally, we obtained caregiver proxy ratings of patients.

*Socio-demographic characteristics:* As expected, the patients were predominantly young, less educated, less likely to be married, more unemployed, and ill for several years [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]

### *Differences in QOL:*

#### *Comparison with other studies:*

The WHO 23 –country data included results for subjects from developing and developed countries [25]. Using scores adjusted for age and sex, our patients had similar scores with the WHO data for sick persons, for physical health (13.1, each) and psychological (13.6 vs 13.7) domains, but less than the WHO data for social relations (13.4 vs 14.0) and environment (12.1 vs 13.8) domains. (Tests of significance difference could not be done because N for WHO data was not provided in the report). Also, the tendency for Sudanese diabetic patients (N = 243) assessed in a previous study[21], to have higher scores than our patients, for the general facet, physical health, psychological and social

relations domains did not reach significance ( $P > 0.05$ ). Diabetic patients had significantly higher scores for the environment domain (Effect size: 95% C.I., 0.36: 0.18 – 0.53). However, our epilepsy patients had significantly higher scores than 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 diabetes mellitus and multiple sclerosis patients[35].

The rather poor QOL in epilepsy (50.6% - 60.8%) could be accounted for by the group's chronicity (mean duration of illness, 10.7 yrs), their social under-achievement, the noted impact of life-long social stigma [1,36], and possibly, the absence of fee –subsidy services[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 studies on the phenomenon of benefit finding (i.e., 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 overwhelming 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].

#### *Socio-demographic and clinical correlates of QOL*

First, higher QOL was 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 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].

*Predictors of patients’ and caregivers’ QOL:*

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. Such an explanation would not suffice for the successful prediction of the caregivers’ QOL. However, this finding is in line with “expressed emotions” research in psychology[18], as well as reports indicating that patient –caregiver characteristics do impact on each other’s QOL [12,15].

To account for the predictive power of caregiver’s proxy rating, we speculate that recent brain –behavior findings about “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 (i.e., 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.

### **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 remedy 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[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 caregivers.

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