

ORIGINAL STUDY

Quality of life in people with epilepsy in Sudan: An example of underserved communities in developing countries

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ABSTRACT

Objectives: The aim of this study was to investigate the quality of life (QOL) in people with epilepsy (PWE) living in Khartoum State, Northern Sudan. The region offers a model of urban and suburban communities in developing countries.

Methods: A cross-sectional study was carried out in the neurology clinic of Khartoum State Hospital and Omer Ibn Alkhatib Health Center in the suburb of Khartoum State. We interviewed PWE living in the city, the suburbs and adjacent villages. Our subjects were known to have been on antiepileptic drugs (AED) for at least 6 months. The impact of epilepsy on the QOL was assessed in the clinic using a 23-item questionnaire with graded scales and check-lists to explore demographic characteristics, seizure control, adverse effects of antiepileptic medication, physical harm, social and psychological impact and stigmatization.

Results: Fifty-two females and 48 males between the ages of 10 and 80 years were interviewed. Sixty percent of participants were between 20 and 39 years of age. While on AED treatment, 63% developed at least one seizure at any given time, 49% in the past 6 months and 27% in the past week. Twenty six percent experienced one or more side effect of AEDs. A significant number of respondents admitted that epilepsy had a negative impact on several aspects of their daily life activities, education and social functioning. Of individuals eligible for work, 17% were unemployed or had their job terminated because of epilepsy. Relationships with spouses were affected in 20 % of cases. Fifteen percent felt stigmatized by their illness. None of the participants had received any formal health education or counseling about epilepsy.

Conclusion: Epilepsy has a significant impact on several aspects of QOL, particularly physical injury and socioeconomic functioning affecting PWE living in

Khartoum State. Poor seizure control, a risk factor for impaired QOL, was common. The overall perceptions of QOL and self satisfaction as stated by our PWE was more favorable when compared to those in developed countries and the Gulf. Nevertheless, this could be more reflective of social circumstances and better seizure control, health education and counseling for PWE and their families is still encouraged and recommended.

INTRODUCTION

Epilepsy is a common, chronic neurological disorder that has a significant negative impacts on the physical and psychosocial wellbeing of affected individuals. People with epilepsy (PWE) are more prone to physical injury, adverse effects of medication, mental distress and restrictions in common social rights. Constrained health and technical resources and prevalent cultural misconceptions impart more disadvantages to PWE in developing countries. Specifically, epilepsy as a health problem may receive less attention and standard care because of many other prevailing priorities.¹

In the preceding two decades, various instruments and inventories for measuring the quality of life (QOL) in PWE have been developed and implemented mainly in North America and Western Europe.²⁻⁴ A few reports came from the Middle East⁵ and Africa.⁶⁻⁷ In this study we interviewed a population of PWE attending a central hospital and a suburban health center in northern Sudan to assess disease-related elements that could impair their QOL and how they personally perceived the dysfunctions imposed.

METHODS

The study was an observational, hospital-based study conducted in the neurology clinic of Khartoum Hospital and in Omer Ibn Alkhatib Health Center in the suburb of Khartoum State during the period from the first of September, 2009, to the end of February, 2010. Qualified medical faculty staff neurologists oversee the clinics. The clinics receive patients from the city center, the suburbs and adjacent villages. We interviewed consecutive patients > 10 years having the diagnosis of epilepsy and consuming antiepileptic drug(s) (AED) for at least 6 months. We excluded patients who were younger than 10 years or older than 80 years of age, had a co-morbid disease expected to significantly affect health and hence QOL, and who exhibited language barriers in the absence of a suitable interpreter. A 23-item questionnaire with checklists and graded scales was used by the interviewer (MS) in the clinic. The questions included details on demographic characteristics, seizure control, adverse effects of antiepileptic medication, seizure-related physical harm,

stigmatization and social and psychological impacts of epilepsy. To estimate epilepsy control, participants were asked if they had experienced one or more seizures in the preceding week and 6 months. We adopted this crude semi quantitative measurement because it was not possible to obtain reliable and accurate seizure counts. The participants were asked to estimate the impact of each item as "a lot," "moderate," "a little" or "not at all." They were finally asked to represent how they perceive their overall QOL on a happy/sad face visual analogue scale.

Ethical approval of the study was obtained from the University of Medical Science and Technology. Verbal consent from participants was obtained after explaining the purpose and the contents of the questionnaire. To secure confidentiality, the respondents were represented by their serial number, and their names were not entered in the questionnaire sheets. The collected data was entered in a flow sheet, and the means and frequencies of variables were determined using the software Statistical Package of Social Sciences (SPSS17).

RESULTS

A total of 100 PWE, 52 females and 48 males, aging between 10 and 80 years (X) were included in the study. The median age studied was 25 with a mean of 27.5 ± 12.2 SD. Sixty percent of the participants were between 20 and 39 years old (Figure 1). Among the adults above 20 years of age ($n = 74$), 15 (20.3%) were married and 2 (2.7%) were divorced.

Seizure control and related events

At any time after starting AEDs, and while taking the prescribed treatment, 63 participants had experienced one or more seizure attacks, 49 had seizures within 6 months and 27 within the week preceding the interview. Twenty-six patients admitted that they experienced one or more of the listed side effects of the AEDs prescribed. During a seizure, 9 participants sustained minor burns, and there were 23 scalp injuries, 5 tooth traumas and

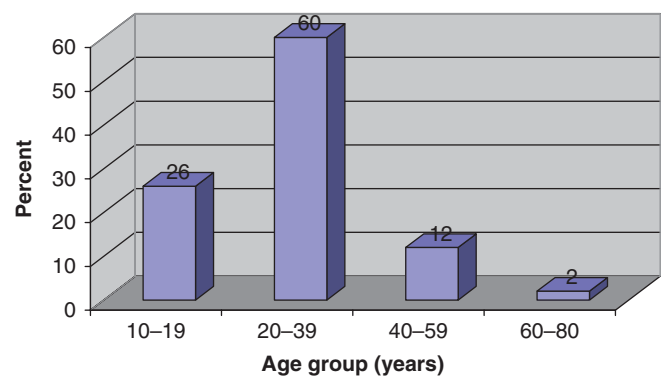


Figure 1. Distribution of age group in people with epilepsy.

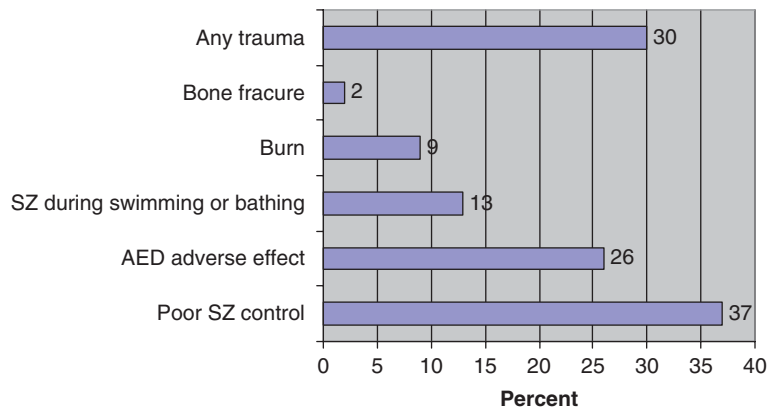


Figure 2. Physical injury seizure-related adverse effects in people with epilepsy. Source: SZ: seizure AED: antiepileptic drug.

2 bone fractures. Life threatening situations were encountered by 13 participants, who developed seizures while swimming or bathing (Figure 2).

Perceived impact

The majority of PWE admitted that the illness did not significantly affected their relationships with their spouses, other family members or friends but about half of them believed that the disease had impaired the progress of their education, career and daily life, in general their socioeconomic activities, e.g. work, sport, travel, society activities (Figure 3). Fifteen PWE felt stigmatized. The overall perception of QOL by the participants did not correlate with the degree of socioeconomic impact since the majority (n = 97) admitted happiness or indifference whereas only one was very unhappy and two were unhappy.

DISCUSSION

The adverse effects of chronic illnesses commonly extend beyond those related to physical health. In reality,

such conditions derange socioeconomic and psychological wellbeing and ultimately jeopardize the QOL of the individual affected. Increasing global awareness of the importance of monitoring QOL in PWE has emerged in recent decades, and various assessment tools and scales have been developed.²⁻⁵ The evaluation is commonly performed via direct patient interview or through a questionnaire. Only a few reports on QOL came from the Middle East⁶ and Africa^{6,8} despite the fact that PWE within these regions are more likely to face more health care and sociocultural disadvantages than their counterparts in Western communities.⁹⁻¹² Cross-cultural and between-country comparison studies had revealed variegated impacts on QOL of PWE across different ethnic groups.^{6,13} Therefore, we included in the questionnaire easily comprehensible questions that were adapted to the conceptual views and limitations of our local participants and at the same time adequately addressing the research objectives.

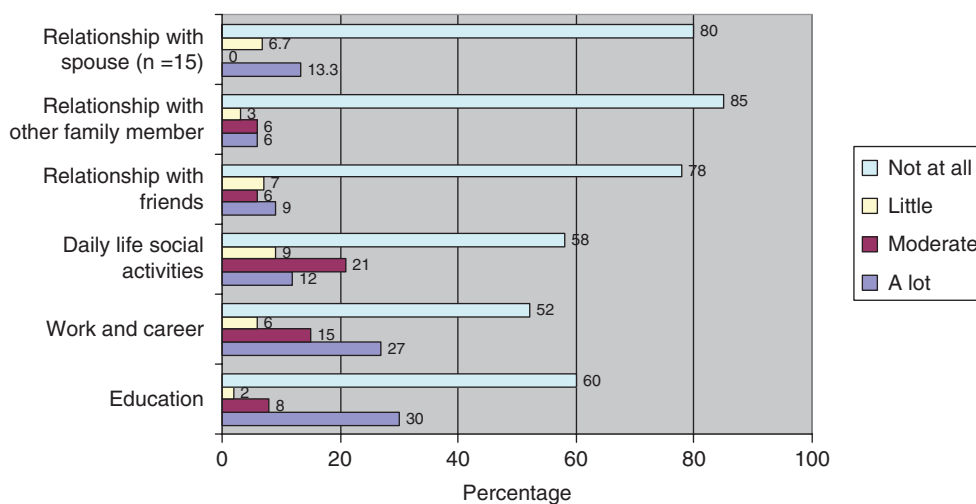


Figure 3. Social and socioeconomic impact of epilepsy on people with epilepsy.

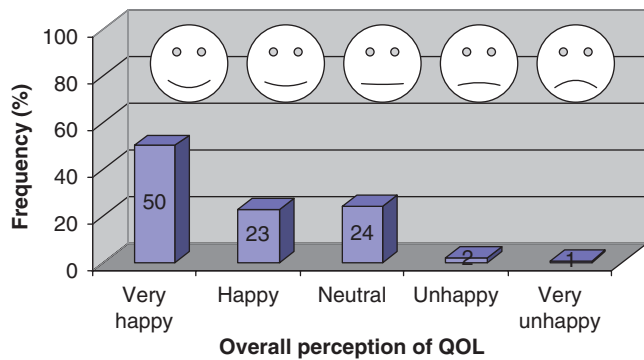


Figure 4. Overall perception of quality of life by people with epilepsy on a visual analogue scale.

Recurrence of seizures in approximately half of our PWE within 6 months preceding the interview indicated poor seizure control. Several factors, like patient compliance, management quality, AED availability and product efficacy can be implicated. In PWE, seizure frequency is the major factor in determining the QOL perception related to the disease's impact. Patients with uncontrolled seizures score significantly worse on QOL scales compared with patients whose seizures are in remission.¹⁴ Leidy et al.¹⁵ studied the relationship between seizure frequency and health-related QOL among 139 adult patients with epilepsy. He showed that seizure frequency had a linear negative impact on QOL and that seizure-free adults can have QOL levels comparable with those of the general population. Worrying increased incidences of seizure-related physical injuries, some of which were life threatening, were observed in our patients. Increased risk of injury is directly related to poor seizure control since adults with intractable epilepsy have high rates of injury whereas those under good control with AEDs face the same risk as the general population.^{16,17} According to the WHO, about 80% of PWE in developing countries do not receive adequate treatment for a multitude of reasons including lack of access to or knowledge of AEDs, poverty, poor health infrastructure and lack of trained professionals.^{18,19} To promote compliance with therapy and hence epilepsy control in resource-restricted countries, the WHO recommends the prescription of affordable AEDs like phenobarbitone and phenytoin by physicians or trained paramedical staff.^{18,20}

The inadequate epilepsy control among PWE may not be solely responsible for the incurred physical injuries since some of the harm could have been avoided if appropriate precautionary measures were applied. In the developed world, incidences of seizure-related accidents are much lower,¹⁶ because of better facilities and attention paid to minimize environmental hazards (in cooking, farming, and transport for example). Therefore, education of PWE and

caregivers to strengthen their awareness about self protection in addition to the pharmacological control of seizures is very important in prevention of physical injury.¹ Information on socioeconomic and cultural consequences among PWE living in the third world is scarce and mostly incomplete.¹⁰ The pan European study¹³ showed that seizure frequency is the major clinical predictor and correlates positively with the degree of psychological and social dysfunction. Among our patients, the proportions of those who faced any degree (little/moderate/a lot) of interference with education, work, career and community social functioning (40–50%) were comparable to those observed in the Gulf (40–56%)⁶ and to their European (39–44%) counterparts who have an average seizure frequency of ≥ 1 per month.¹³ The negative impact on the relationship with a spouse among our patients (20%) was approximately the same as that in the Gulf (18%). Impairment of social relations with other family members and friends was much less frequent in our patients (15 and 22%, respectively) compared to that in the Gulf (43% and 41%) and in European PWE who experienced ≥ 1 seizure per month (37 and 40%) but resembled results of European patients who did not have seizures in the past year (16 and 15%). It is difficult to rule out if the interviewee hesitated to disclose their true response when directly asked about sensitive personal issues. Despite the significant physical and socioeconomic derangements incurred by epilepsy, the overall perception of QOL by our PWE was very favorable ranging between very happy and neutral in the case of almost all subjects (Figure 4). It is possible that the empathetic surrounding provided by the extended consanguineous families, typical of our communities, helped to mask some of the external brunt of the social impact.

There are several limitations in this study that hinder extrapolation of the results to the whole population. The study sample is small and hospital-based, hence describing a specific limited population. Moreover, the enrollment process was biased to urban and suburban dwellers and did not include inhabitants of remote rural districts who are expected to face more economic and health care disadvantages. However, the study has highlighted the presence of socioeconomic impact on QOL of our PWE, our recommendation for better control of seizures and the need for scheduled counseling and health education.

DECLARATION

An abstract of this study was presented at the 63rd annual meeting of the American Academy of Neurology, Honolulu, April 2011. *Neurology* 2011;76(Suppl4):A54.

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