STUDENT ORIGINAL ARTICLE

Quality of life among patients with epilepsy attending the epilepsy clinic at the National Hospital of Sri Lanka

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Abstract

Background

Quality of life (QOL) in epilepsy is likely to be affected by the seizure severity but remains inadequately studied.

Objective

To describe the QOL and its association with seizure severity of adults with epilepsy.

Methods

A cross-sectional study was conducted among patients attending the epilepsy clinic of the National Hospital of Sri Lanka from January to March 2019. Patients were recruited using systematic sampling. An intervieweradministered questionnaire, Quality of Life in Epilepsy-10P and Seizure Severity Questionnaire V2.2 were used to record patient data, overall QOL and seizure severity. Perception of success in employment and marriage was explored using separate questionnaires. Scoring algorithms were used to calculate individual and mean scores. Participants with an overall QOL score above the mean were considered to have a 'good' QOL while individuals with seizure severity'. The Chi-squared test was applied in statistical analysis.

Results

One hundred and thirty six patients (53.7% men; mean age 39.0 years, SD=13.9) were recruited. Their mean duration of epilepsy was 19.9 years (SD=14.2), with 47.1% experiencing generalized tonic-clonic seizures. A 'good' overall QOL was observed among 78 patients (57.4%), which was significantly associated with a 'low' seizure severity (p<0.001). However, low seizure severity was not significantly associated with being employed (p=0.403) or perceived success in marital life (p=0.634).

Conclusions

A low seizure severity is associated with a 'good' overall QOL in epilepsy. However, seizure severity did not affect the QOL related to employment or marriage.



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Background

Around 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally [1]. Epilepsy significantly impacts on a person's quality of life because its clinical manifestations are uncertain and variable. World Health Organization defines Quality of Life (QOL) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [2].

The Quality of Life of a person with epilepsy is negatively affected by the factors such as clinical manifestations, stigma, adverse effects of antiepileptic drugs and epilepsy surgery [3,4]. Aspects in life other than physical and mental health including employment, marriage and self-esteem are also affected [3].

Quality of life related to marital status and QOL related to employment can be considered specific entities of QOL. Studies show that people with epilepsy, commonly experience notable problems concerning employment such as unemployment, underemployment and inability to reach the full potential for their qualifications and age [5,6,7]. Remaining single, marital maladjustment and divorce have shown a significant association to the disease duration and psychiatric comorbidity in epilepsy patients [8]. Therefore, the QOL related to employment and marriage requires specific analysis.

Severity of seizures depends on various factors. Being able to predict a seizure, type of seizures, seizure frequency, duration, physical effects, automatism, postictal events and seizure worry has been included in many of the severity assessment tools [9]. Severity of an individual seizure can be considered a disease characteristic that contributes to the QOL of an epilepsy patient.

In Sri Lanka, epilepsy accounts for 1.7% of the chronic illnesses of which nearly half of the patients visited government hospitals for treatment [10]. Owing to the burden on the Sri Lankan health care services and the significant impact on patients' lives in epilepsy, it warrants systematic assessment. This study aimed to bridge the gap in existing knowledge on epilepsy related QOL among patients attending a tertiary care hospital by assessing their overall QOL, QOL related to marital status, QOL related to employment and their association with the seizure severity in a Sri Lankan setting.

Methods

A cross-sectional study was conducted in 2019 among 136 patients attending clinics at the Epilepsy Unit of National Hospital of Sri Lanka (NHSL). Ethical clearance to conduct the study was obtained from the Ethics Review Committee of the Faculty of Medicine, Colombo. Administrative clearance was obtained from the Director of the NHSL and the consultants in charge of the relevant clinics. Patients who were older than 18 years and had been having epilepsy for more than 6 months with at least one clinic attendance previously were included by systematic random sampling. Patients with dementia or other cognitive impairment, patients who had epilepsy due to secondary causes, patients who had undergone epilepsy surgery and patients who did not experience a seizure within past 6 months were excluded.

An interviewer -administered questionnaire including five separate sections that are socio-demographic and clinical characteristics, seizure severity questionnaire, overall QOL, QOL related to employment and marital status was used for collection of data. Two of the five sections included standard questionnaires that were Seizure Severity Questionnaire version 2.2 (SSQ V2.2) [11] and Quality of Life in Epilepsy-10P (QOLIE-10P) [12]; a questionnaire previously validated in an Asian country [13]. Sections regarding socio-demographic and clinical characteristics and QOL related to employment and marriage were developed by investigators. A questionnaire used in a South Korean study [14] was used as a guidance for section on marriage.

Only the baseline version of SSQ V2.2 was utilized to gather data on seizure severity. This consisted of ten main questions that assess seizure severity under four components; before seizures, during seizures, after seizures and overall severity and bother. In 'after seizures' component, cognitive, emotional and physical effects were assessed by the patient's perception on their frequency, severity and bother. Examples for above effects were included in the questionnaire for the convenience of patients. Type of the seizure was determined using semiology of seizures identified with a short clinical history from the patient and the bystander and by referring to the follow-up records. Patients' description of the symptoms included warning signs, activities they experienced and impact on the level of consciousness. These descriptions were supported by the bystanders who had witnessed the patients experiencing a seizure. Section used to assess QOL included questions on health and daily activities, distress felt about problems, worries related to epilepsy and questions on the aspects of the disease that bothered patients. After obtaining informed written consent, data for all five sections of the questionnaire were collected from eligible patients during the clinic waiting hours by the principal investigators.

Data were analysed using SPSS software [15]. Data regarding the socio-demographic factors were presented as descriptive statistics. Total seizure severity score was calculated according to the predetermined scoring algorithm of SSQ V2.2 and individual questions were described. Mean value was used as the cut-off point to

categorize the participants as having "low" and "high" severity. Overall QOL score of each study participant was obtained using QOLIE-10P scoring algorithm and individual questions were analysed by descriptive statistics. Mean and median were more or less similar and the mean value was used as the cut-off point to categorize the participants as having "good" or "poor" overall QOL. Association between seizure severity and overall QOL were assessed using Chi-square test at a significance level of 0.05

Reason for unemployment among those unemployed, perceived impact of epilepsy on employment and perceived impact of epilepsy on marital status were described. The participants who answered "employed", "unemployed" or "self-employed" as their employment status were considered in identifying the association between seizure severity and employment status. Selfemployed group was also considered under "employed" group. Chi-square test was used to identify the association of employment status and perception on success of marital life with seizure severity. Selected questions were used to identify associations.

Results

The response rate for questionnaires was 100%. Sociodemographic characteristics of the participants are depicted in the Table 1.

Socio-demographic char	acteristics	No	%
Age (years)	<40	73	53.7
	40-59	56	41.2
	≥60	7	5.1
Gender	Male	73	53.7
	Female	63	46.3
Ethnicity	Sinhalese	105	77.2
	Tamil	15	11.0
	Muslim	14	10.3
	Burgher	2	1.5
District	Colombo	52	38.2
	Gampaha	39	28.7
	Kalutara	10	7.4
	Non-western province	35	25.6
Level of Education	Never attended school	2	1.5
	Grade 5 and below	8	5.9
	Grade 6-10	38	27.9
	Completed O/L	55	40.4
	Completed A/L	33	24.3

 Table 1. Socio-demographic status of the participants (n=136)

(Continued)

Employment Status	Employed	62	45.6
	Unemployed	34	25.0
	Self-employed	8	5.9
	Retired	4	2.9
	Student	9	6.6
	Housewife/Househusband	19	14.0
Monthly Income	Less than Rs.10000	4	5.7
	Rs.10000 - Rs.25000	24	34.3
	Rs.25000 - Rs.50000	36	51.4
	Rs.50000 - Rs.100000	5	7.1
	More than Rs.100000	1	1.4
Marital Status	Never married	51	37.5
	Married	77	56.6
	Divorced	3	2.2
	Widowed	5	3.7

The mean age of the study sample was 39 years (SD=13.9 years). Mean duration of the disease in the study subjects was 19.91 years (SD=14.15 years). Participants were categorized according to the type of seizure they were having as Focal Onset with Retained Awareness, Focal Onset with Impaired Awareness and Generalized Onset. Majority (64, 47.1%) were having Generalised Onset seizures.

Mean total seizure severity score of the patients with epilepsy was 2.92 (SD=1.359). High seizure severity was seen among 48.5% (n=66) of the patients and 51.5% (n=70) of the patients were having low seizure severity. Regarding the pre ictal phase a total of 75 participants (55.1%) had an aura before the seizure, out of whom 30 participants (40%) said that the aura was "helpful" to prepare for the seizure, 22 participants (29.3%) said that the aura was "somewhat helpful", while 23 participants (30.7%) said that it was "not helpful".

Movements or actions such as automatic movements, uncontrollable actions, falling, injury, tongue biting, wetting pants with urine etc., were present in 91 (66.9%) subjects during the seizures and of them, 23 (25.3%) said that those were 'severe' and 29 (31.9%) responded that the movements were 'bothersome'. Forty four (13.6%) participants had only altered consciousness or sensations during seizures and out of them, only 6 (13.6%) mentioned that those periods were 'bothersome'.

Cognitive effects were present in 71 (77.2%) subjects whereas emotional effects were present in 55 (59.8%) subjects after the seizures. Eighty (87.0%) subjects experienced physical effects after seizures. Majority had moderate severity in cognitive (32, 45.1%) and physical (39, 48.8%) effects while having mild severity in emotional (20, 36.4%) effects. Overall severity and bother was "very severe" for 27 (19.9%) subjects while for 45 (33.1%) subjects, effects were "very bothersome".

Majority; 71 (52.2%), responded "activities during the seizures" was the most bothersome part regarding the seizures other than "warning (aura) before seizures" and "recovery after the seizures". This was similarly higher in subgroups of patients with low seizure severity and high seizure severity.

Table 2 summarizes descriptive statistics of the answers given by participants for questions related to QOL.

Perception	Participants responses* No. (%)					
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you have lot of energy?	51 (37.5)	20 (14.7)	25 (18.4)	14 (10.3)	13 (9.6)	13 (9.6)
Did you feel downhearted and low?	4 (2.9)	17 (12.5)	35 (25.7)	16 (11.8)	9 (6.6)	55 (40.4)
		A great deal	A lot	Some- what	Only a little	Not at all
How much did the epilepsy or effects of AED** cause trouble with driving or travel?		13 (9.6)	18 (13.2)	20 (14.7)	17 (12.5)	68 (50.0)
		Not at all bother- some [1]	[2]	[3]	[4]	Extremely bother- some [5]
How much do the work limitations bother you?		58 (42.6)	29 (21.3)	18 (13.2)	18 (13.2)	13 (9.6)
How much do the social limitations bother you?		70 (51.5)	25 (18.4)	17 (12.5)	10 (7.4)	14 (10.3)
How much do the memory difficulties bother you?		53 (39.0)	19 (14.0)	31 (22.8)	22 (16.2)	11 (8.1)
How much do the physical effects of AED bother you?		85 (62.5)	11 (8.1)	18 (13.2)	11 (8.1)	11 (8.1)
How much do the psychological effects of AED bother you?		96 (70.6)	10 (7.4)	15 (11.0)	8 (5.9)	7 (5.1)
			Very afraid	Some- what afraid	Not very afraid	Not afraid at all
How afraid are you of having a seizure within next 4 weeks?			18 (13.2)	35 (25.7)	25 (18.4)	58 (4.6)
		Very good	Pretty good	Good and bad equal	Pretty bad	Very bad
How has your QOL been during past weeks?		37 (27.2)	43 (31.6)	43 (31.6)	10 (7.4)	3 (2.2)

Table 2. Perception on overall quality of life among participants (n=136)

* All responses are on Likert scale

** AED = Anti-Epileptic Drugs

Frequency distribution of total overall QOL score of the participants is shown in Figure 1.

score was associated with having a low seizure severity score. It was found that having a good quality of life was significantly associated with having a low seizure severity (p < 0.001). Chi squared test applied is depicted in Table 3.

There were 78 (57.4%) patients with good QOL and 58 (42.6%) patients with poor QOL. Having a good QOL



Figure 1. Frequency distribution of total overall QOL score of patients with epilepsy

Table 3 Association	of seizure	severity with	overall QOL	, perception	on marriage	and
	employm	ent status am	ong epilepsy	patients		

		Se			
		Low No. (%)	High No. (%)	Total N	Significance
	Poor	17 (24.3%)	41 (62.1%)	58	$\chi^2 = 19.88$
Overall QOL	Good	53 (65.7%)	25 (37.9%)	78	df = 1
	Total	70 (100%)	66 (100%)	136	p < 0.001
	Epilepsy interfered	10 (26.3%)	8 (21.6%)	18	$\chi^2 = 0.266$
Perception on marriage*	Epilepsy did not interfere	28 (73.7%)	29 (78.4%)	57	df = 1
	Total	38 (100%)	37 (100%)	75	p = 0.634
	Unemployed	15 (28.9%)	19 (36.5%)	34	$\chi^{2} = 0.699$
Employment status**	Employed	37 (71.1%)	33 (63.5%)	70	df = 1
	Total	52 (100%)	52 (100%)	104	$\mathbf{p} = 0.403$

* Only married patients are included

** Students, retired patients and housewives/househusbands were excluded

Among the participants who were either "unemployed" or "househusbands/housewives" (n=53), when asked whether they were unemployed due to their illness; 21 (39.6%) answered "very much" and 7 (13.2%) answered "somewhat". Eighteen (34.0%) said their disease was "not at all" a reason for their unemployment. As shown in Table 3, having a high seizure severity was associated with being unemployed, but it was not statistically significant (p=0.403).

Majority of the married participants (47, 61.0%) declared that epilepsy did not interfere at all in having a successful marital life. Fifty three (84.1%) participants said epilepsy was not a factor that influenced them to restrain from having children or to limit the number of children. Epilepsy did not interfere at all in having children for 47 (74.6%) participants. Twenty five participants (46.3%) who were unmarried or divorced thought that epilepsy would be a negative factor for their marriage or marriage negotiations. As shown in Table 3, epilepsy being an interference to a successful marital life was associated with having low seizure severity. It was not statistically significant (p=0.634).

Discussion

Our study found that good QOL of the patients having epilepsy was determined by the low seizure severity they were experiencing. Overall QOL of patients being followed up at a tertiary care hospital was significantly associated to the severity of an individual seizure. Majority of the patients were found to have a good overall QOL with highest impact related to daily activities. Majority of the patients had low seizure severity which was majorly affected by the activities during the seizure. Quality of life related to marriage and employment was affected by the disease in these patients but did not show a significant association to the severity of individual seizures.

In our study the most bothersome component of the seizure for the majority was 'activities during the seizures'. This was in contrast with the findings of a study done in Bulgaria using the SSQ questionnaire where the most bothersome part was 'recovery after the seizures' [16]. This is possibly due to cultural differences between the two study populations.

A higher percentage of patients chose mental function (thinking, concentrating and memory) as an important aspect of their seizure in our study which is consistent with the findings of a Russian study [17]. Seizure worry was identified as a significant factor influencing QOL in studies conducted in USA, Russia and India [17-20]. In contrast, seizure worry was one of the least important factor affecting QOL in our sample. This could be due to proper management, follow-up and cultural differences. Participants' perception of overall QOL in our study was more towards the positive end.

Our study found that having a good QOL was significantly associated with having low severity. Low severity in our context was having less severe and less bothersome effects before, during and after a seizure attack. Previous studies had focused on the association of QOL with parameters like seizure worry, type of treatment, medication effects and seizure frequency that are not confined to a single seizure attack but represent the overall illness [4,17,21]. We have included these aspects into the score by the means of patients' perception on 'severity and bother', but a significant value has been given to effects before, during and after seizures.

Our study showed an unemployment rate that was almost five times higher than the general population [22]. Nearly half of the unemployed said that they were unemployed due to their illness 'somewhat' or 'very much'. This rate is higher than in a European study [3] where only a quarter of the participants believed that epilepsy was the cause of unemployment. One possible reason for this could be difference in the culture of the two countries. Out of the employed, the percentage of patients that believed they had to 'reduce or stop work due to epilepsy' were almost similar to the findings of the European study [3] and the Indian study [6]. In our study, job satisfaction was found to be lesser among the participants than in India, possibly due to the different approach in the questionnaire. Participants' employment status was considered as a measure of QOL related to employment status which is a limitation of our study.

In our study, the divorce rate was about seven times more than the general population [23]. Majority of the patients gave positive answers regarding having and raising children which is consistent with the study done in Korea [14]. Our study had a higher percentage of married patients who said that epilepsy did not interfere for a successful marital life as in the study done in Brazil [8]. Only this aspect was used in identifying the association with seizure severity which might be a reason for the association not to be significant.

Although SSQ V2.2 and QOLIE-10P have not been validated for Sri Lanka using validation techniques, it underwent cultural adaptations before its use, by a group of experts during which some items in the translated tools were re-worded to suit the local culture. Pre-testing among the target group was also done. There could be underestimations of the seizure severity related to overall QOL, employment and marital status, as this was a clinic based population who were taking medications and therefore, better controlled than the normal epileptic patients. This may restrict the feasibility of generalization of study findings into the population.

Conclusions

A good QOL is seen among the epilepsy patients who are being followed up at a tertiary care centre which is significantly associated with the low seizure severity seen among a majority.

However, the 'low' seizure severity was not significantly associated with being employed or epilepsy being an interference for a successful marital life. Appropriate treatment and proper follow up to reduce seizure severity, social and family support, employment guidance services and occupational therapy to improve the QOL of patients are recommended.

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