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Health related quality of life in patients with epilepsy in Turkey

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Abstract. [Purpose] This study measured the quality of life in epilepsy and determined associated demographic and clinical factors by means of the Short Form-36 health survey. [Subjects and Methods] 124 consecutive epilepsy patients were enrolled and their demographic variables and clinical characteristics recorded. The Short Form-36 questionnaire was completed independently by each participant. Short Form-36 dimensional and composite scores were computed and scaled with data from an extensive survey of the healthy population. [Results] Short Form-36 scores for physical dimensions were similar to healthy values, but those for mental dimensions except for energy/vitality were remarkably and significantly lower than normal. All Short Form-36 average scores for women were lower than those for men and significantly so for mental health composite scores. Patients responding well to treatment were aware of their improving health as measured by the Change in Health score and had better dimensional scores than those with a poor response. [Conclusion] Patients with epilepsy do not perceive impaired physical health status. However, their mental health appears vulnerable, especially in women. Therefore, the major burden in epilepsy is in the mental health category. A positive treatment response is also an important determinant of the related quality of life measure.
Key words: Epilepsy, Quality of life, SF-36

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INTRODUCTION

Successful treatment is traditionally assessed by the extent of seizure control. However, quality of life (QoL) has recently attracted more attention because it reveals complaints regarding attention, learning, physical pain, anxiety, and sleep[1].

Health related QoL-associated factors for epilepsy have been linked to adverse drug effects[2, 3], demographic variables, concurrent medical, psychiatric[4–6] and psychosocial problems[7], onset of seizures early life, loss of consciousness during seizures[8, 9] and the frequency of seizures[2, 8].

The Short Form-36 (SF-36) Health Survey is the most widely used generic self rating[10] and internationally recognized global measure of QoL[11–15]. The SF-36 consists of 36 questions, has the advantages of easy administration and ability to measure the impact of a disease and related treatments on both physical and mental health[15, 16]. It has been validated for measuring health perception in a general population[17], translated and validated for use in more than 40 countries, including Turkey[18].

The present study aimed to determine QoL and associated demographic and clinical factors in an epilepsy cohort in a tertiary epilepsy center by means of the SF-36.

SUBJECTS AND METHODS

Subjects

This was a prospective, case-control study. Consecutive patients admitted to the epilepsy outpatient clinic during the study period (October 2013 to April 2014) were enrolled. Those who were illiterate, mentally retarded or who had concomitant chronic systemic diseases were excluded.

This study was approved by the Istanbul University Ethics Committee (Ref. B.30.2.IST.0.30.90.00/4450). All participants gave their informed consent.

The clinical types of epilepsy syndromes and seizures were identified according to 1981 and 1989 ILAE classifications, respectively[19, 20]. Age, gender, level of education, marital and occupational status, age at disease onset, disease duration, and treatment in the last year were recorded. Poor response to treatment was defined as the occurrence of a seizure without any inciting factor whereas good response was defined as freedom from seizures.

The participants themselves completed the questionnaire alone in a room. One researcher trained in the application of this questionnaire retrieved each form just after its completion.

SF-36 questionnaire evaluation provides separate raw category scores on a scale of 0 to 100 for eight aspects (dimensions) which have been defined as Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health perception (GH), Energy-Vitality (VT), Social Functioning (SF), Role-Emotional (RE) and Mental Health (MH)[15]. It provides scores for predominently "physical" (PF, RP, BP, GH) and "mental" (VT, SF, RE, MH) dimensions. Change in Health (CH) perception during the last year is also assessed by evaluating a five-level graded response to a single question. Summary measures of physical and mental health are constructed by computing Physical (PHC) and Mental (MHC) Health Composite scores as differently weighted averages of the eight SF-36 dimensional scores[21].

Data evaluation and Statistical analysis: All raw scores were scaled with normative statistical data obtained from a large sample of the healthy population[18]. The scaling procedure used normalizes each raw and composite score with respect to a mean equal to 50 representing the healthy population normative average score and to 10 units of scaled standard deviation (SD) equivalent to one SD of the normative sample[22]. By this definition, all scaled dimensional and composite scores have a mean of 50 and SD of 10 for the healthy population. Thus, each 10-point score difference from 50 represents one SD from the healthy population mean score: e.g. a patient scoring 30 is 2 SD below normal i.e. at the same level as the bottom 2.5% of a normally distributed healthy population.

Statistical significance was calculated using Student's t-test when distributed homogeneously and using Mann Whitney U test when distributed heterogeneously for numerical data (the choice was made by the use of the F-test), the χ^2 was used for non-parametric data. Pearson' linear correlation was constructed to analyze the relationship between demographic/clinical features and SF-36 subscale and total scores.

RESULTS

During the survey period, 154 patients were enrolled. Results for 30 patients were not included as 13 could not complete the SF-36 questionnaire appropriately, seven had conversion disorders and 10 had nonepileptic diseases. Data from the remaining 124 patients (57 males, 46%) were subjected to statistical analysis (Table 1).

Overall analysis –QoL results for all epilepsy patients: SF-36 scores for physical dimensions PF and BP as well as for PHC of patients with epilepsy were similar to healthy population values (Table 2), but those for RP and GH were lower by 1/2 SD (both p≅0). However, SF-36 scores for MHC and for all mental dimensions except VT were ≈1 SD lower than normal (all p≅0).

Dispersions of SF-36 scores around their mean were similar (9.3≤SD≤11.8, p<0.01) to those of the healthy population (SD≡ 10) except for SF (SD = 6.2, p≅0).

Subgroup analysis -QoL results according to demographic characteristics: Almost all SF-36 average scores were lower for female patients but were more significantly different from those of males only for VT (p<2%) and MHC (p<5%) (Table 2). No dissimilarities due to marital status and occupation were detected.

Subgroup analysis -QoL results according to clinical characteristics: No dissimilarities due to the treatment method or epilepsy and seizure types were detected. SF-36 scores for patients with generalized and partial epilepsy were similar except for SF which was lower in generalized epilepsy patients.

Subgroup analysis -QoL results according to response to treatment: Significant disparity in GH, VT, MH (all p<1%) and MHC (p<2%) scores were found in favor of patients who responded positively to treatment compared to those not treated or who did not respond well to treatment (Table 3). While the CH for untreated and non-responsive patients (51.2±11.1) was within the expected range, CH for responsive patients (56.8±9.9) was significantly higher (p<5%).

Correlation analysis: No SF-36 score was found to be correlated with age at assessment, age at onset, disease duration or level of education. Moreover, no such correlations were found in the segregated in the data segregated by gender.

Table 1. Demographics and clinical characteristics of the epilepsy patients (n=124)

Demographic variables		Clinical variables	
Age at follow-up (years)	27.1 ± 11.4	Disease duration (years)	8.3±9.0
Gender (Male–Female)	57 (45%)–67 (55%)	Age at onset (years)	18.8±9.9
Education		Type of epilepsy	
≤5 years	36 (29%)	Partial	78 (63%)
≤8 years	25 (20%)	Generalized	20 (16%)
≤11 years	32 (26%)	Unknown	26 (21%)
≤15 years	29 (23%)	Type of seizure	
>15 years	2 (2%)	CPS	35 (28%)
Work status		SGTC, GTC	15 (12%)
Working	32 (26%)	CPS, SGTC, SP	30 (25%)
Not working	53 (43%)	Absence, Myoclonus, GTC	20 (16%)
Student	34 (27%)	Unknown	24 (19%)
Unknown	5 (4%)	Number of AEDs	
Marital status		Polytherapy	32 (26%)
Married	43 (35%)	Monotherapy	63 (51%)
Single	53 (43%)	No treatment	3 (2%)
Widow	3 (2%)	Unknown	26 (21%)
Pediatric (<18 years)	16 (13%)	Response to treatment	
Unknown	9 (7 %)	Good	47 (38%)
		Poor	45 (36%)
		Unknown	32 (26%)

AED: antiepileptic drugs; CPS: complex partial seizure; SGTC: secondary generalized tonic-clonic; GTC: generalized tonic-clonic; SP: simple partial

Table 2. Health quality of life in all epilepsy patients and comparisons according to gender

Parameters[†]	All cases (n=124)	Male (n=57)	Female (n=67)
Physical Function (PF)	48.6±10.2	49.4± 9.1	47.9±11.1
Role Physical (RP)	45.2±11.5*	46,4±10.3	44.2±12.4*
Body Pain (BP)	49.8±11.2	51.2±10.1	48.7±12.1
General Health (GH)	44.2±9.7*	44.3±10.0*	44.0±9.5*
Energy / Vitality (VT)	48.5±10.9	51.2±11.1 ¶	46.3±10.3*
Social Function (SF)	37.0±6.2*	36.9±6.5*	37.0±6.1*
Role Emotional (RE)	42.8±11.8*	44.8±10.7*	41.1±13.2*
Mental Health (MH)	40.2±11.6*	42.1±11.0*	38.6±12.0*
Change in Health (CH)	53.2±10.0*	54.5±9.4	52.0±10.4
Physical Health Composite (PHC)	49.9±9.3	50.2±9.1	49.6±9.6
Mental Health Composite (MHC)	39.3±10.2*	41.4±10.0* ¶	37.5±10.2*

[†]All scores are shown as mean±standard deviation (SD) and scaled with respect to those of reference healthy population whose normalized scores are 50±10 i.e. a 10-point score difference represents one SD.
*Significantly different from healthy population value (p<0.05, Student's t-test)
¶Significantly different from women (p<0.05, Student's t-test)

DISCUSSION

In the present study, patients with epilepsy rated their physical status at the same level as that of a healthy population as indicated by almost normal SF-36 PHC scores. SF-36 physical dimension scores only reflected significant weakness in GH and RP dimensions. All physical dimension scores were gender-insensitive. In contrast, Mental Health Composite and all predominantly mental SF-36 dimension scores, except for VT, were found to be significantly ≈1 SD below mean healthy levels. Among these, uniformly (low dispersion) worse by ≈1.5 SD and gender insensitive Social Function (SF) dimension scores were especially notable since they indicate to a remarkably low self-perceived social status. Women with epilepsy had

Table 3. Comparisons of health quality of life according to response to antiepileptic treatment.

Parameters[†]	Good response (n=47)	Poor response (n=45)
Physical Function (PF)	49.6±8.7	47.7±11.1
Role Physical (RP)	46.6±11.1	43.5±11.9
Body Pain (BP)	52.2±9.5	49.2±11.7
General Health (GH)*	47.9±8.5	41.3±8.4
Energy / Vitality (VT)*	51.9±11.3	45.6±9.9
Social Function (SF)	36.0±6.1	38.0±7.2
Role Emotional (RE)	43.5±11.6	40.9±13.6
Mental Health (MH)*	44.0±11.1	36.4±11.1
Change in Health (CH)*	56.8±9.9	51.2±11.1
Physical Health Composite (PHC)	51.6±7.8	49.0±9.8
Mental Health Composite (MHC)**	41.4±10.0	36.6±9.8

[†]All scores are shown as mean±standard deviation (SD) and scaled with respect to those of reference healthy population whose normalized scores are 50±10 i.e. a 10-point score difference represents one SD.
*Significant difference exists between groups, $p<0.05$, Student's t-test
**Significant difference exists between groups, $p<0.05$, Mann-Whitney U-test

consistently lower QoL scores than men and significantly so for VT and especially for MHC indicating greater mental health vulnerability.

The efficacy of two generic (SF-36 and SF-12) and two specific epilepsy-targeted QoL measures (QoLIE-89 and Qo-LIE-31) were previously compared in epilepsy[23]. SF-36 scores yielded comparable responsiveness indices for assessing the degree of freedom from seizures. Generic QoL measures such as SF-36 correcty reflect the perspective of patients for many diseases, including neurological conditions such as epilepsy[24–26]. Another major advantage of SF-36 is the ability to compare the QoL of epilepsy patients with that of the healthy population[17, 23].

Our results partially correlate with previous literature. In a smaller cohort of epileptics with partial seizures who responded well to treatment, all SF-36 physical dimensions were found to be normal whereas mental dimension scores were negatively affected[27]. In one study, men had lower scores for physical functions than women[28]. The selective negative impact of the disease on social dimensions of the patient QoL is probably due to reported development of depressive symptoms in patients with epilepsy[29, 30]. Still lower scores for women may be linked to recent findings of higher incidence of depressive symptoms in female patients with epilepsy[31].

The frequency of seizures consistently appeared to have an impact on QoL[28, 32–34]. Furthermore, seizure freedom was suggested to be necessary to improve QoL after epilepsy surgery, but little is known regarding the seizure-frequency reduction needed to improve QoL among medically treated individuals[23]. The present study may help clarify the impact of response to treatment on QoL since subgroup analysis supports the positive impact of good response to treatment on the QoL of epilepsy patients. Indeed, the patients who responded well to treatment were aware of their improved physical health as indicated by their significantly better SF-36 GH dimension and CH scores while patients with a poor response had significantly lower scores in these dimensions. Neither seizure type nor the the number of antiepileptic treatments had an effect on the poor QoL in this latter group. Their mental health was also more affected than their physical health while patients responding well to treatment had significantly better SF-36 mental dimension scores. Good response to treatment probably changes the patient's opinion about the disease while poor response and its unfavorable impact on social and occupational life introduce more psychological burdens. Thus, the need for psychological support is greater and should be recommended for the group with a poor treatment response; indeed, some limited positive outcome of psychotherapy on the fatigue/vitality (VT) dimension has recently been observed[29].

Seizure severity was previously reported to be a significant predictor of QoL along with depression but not the response to treatment[35]; this difference from the present work may originate from the use of different scales or definitions for seizure freedom. It has also been claimed that seizure-free adults can have QoL levels comparable to those of the general population[27]. This is not confirmed by our results which show that although a significant improvement of QoL indices is observed concurrently with good response to treatment, significant differences in the QoL as compared to that of a healthy population were still preserved in social dimensions.

Interestingly, our results do not indicate that type of epilepsy, type of seizures, age at onset, disease duration, work status, education level or treatment modality have an impact on QoL. These findings contrast with those of previous studies which found longer disease duration, advanced age, lower education level, use of polytherapy, presence of adverse effects[36] and psychosocial factors[32] to be correlated with lower QoL.

Finally, this study points to mental health as the major burden in epilepsy and finds that response to treatment is an important QoL determinant for affected patients.

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