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The Greek version of the Quality of Life in Epilepsy Inventory (QOLIE-31)

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Abstract

This study is presenting the translation and cultural adaptation into Greek of the Quality of Life in Epilepsy Inventory (QOLIE-31). We adapted the QOLIE-31 to Greek through a procedure of translation–back-translation. Sixty-three patients were interviewed and completed the QOLIE-31 and the GHQ questionnaires. We re-examined a subset of them after a period of 2–5 weeks to evaluate the test–retest reliability of the questionnaire. We assessed the convergent validity by comparison of the QOLIE-31 and the GHQ and QOLIE-31 subscales and external measures. Discriminative validity was evaluated using the method of known-groups comparisons. The internal consistency was high for the QOLIE-31 and its' subscales (Cronbach's α 0.92 and 0.59–0.83 respectively). Test–retest reliability was acceptable (intra-class correlation coefficient 0.49–0.89 and Pearson's coefficient 0.53–0.92) for the group of patients who were re-examined. Comparison of the QOLIE-31 and GHQ scores showed agreement between the two questionnaires (Pearson's coefficient −0.61). We demonstrated the discriminative validity by the difference in the QOLIE-31 scores between patients with different seizure frequencies and different employment status. We concluded that the Greek version of the QOLIE-31 has psychometric properties equivalent to those of the original American-English version and is a valid and reliable instrument.

Key words: Epilepsy, Greek, Psychometric properties, QOLIE-31, Translation

Abbreviations: QOLIE-31 – Quality of life in epilepsy inventory; GHQ – General health questionnaire; QoL – Quality of life; AED – Anti-epileptic drug

Introduction

Recently, researchers have recognized that epilepsy has a greater impact on quality of life (QoL) in comparison to other chronic diseases. This is partly because of the unpredictability of seizures and partly because of the stigma, which may, even in modern societies, be associated with the diagnosis of epilepsy [1, 2]. When it comes to defining QoL, in particular health-related QoL, most researchers agree that it cannot be expressed in a single word or phrase [3–5] and should incorporate several domains, such as physical functioning, social and occupational functioning, cognition, psychological status, energy and general well-being.

Several instruments that measure either generic or disease specific QoL have been developed. The Quality of Life in Epilepsy Inventory (QOLIE-31) is a self-completed questionnaire designed for epileptic patients. It was derived from a longer instrument, the QOLIE-89, created by the QOLIE Development Group in 1993. It contains seven subscales which address the following aspects: emotional well-being, social functioning,

energy/fatigue, cognitive functioning, seizure worry, medication effects and overall quality of life [6]. The score (in values between 0 and 100) is calculated for each subscale and for the total (by using a weighted mean of the subscale scores) so that higher values represent better QoL. The instrument was originally created in the United States, but it has been translated into various languages [7–9] and adapted for use in different populations. Its validity and reliability have been documented [10] and the instrument has been and is currently used in numerous clinical studies [11, 12].

The aim of this study was to assess a translation of the instrument, adapted to the Greek population, ensuring the validity, reliability and cultural accuracy of the new version. We chose QOLIE-31 [13] because it is easier to administer than the longer version (with the 89 questions), and has similar psychometric properties; in addition, it is more often used in international studies [14, 15]. The Greek translation might serve as an instrument for use in clinical practice and research protocols. Moreover, it could be applied in projects related to EUCARE (the European Concerted Action and Research in Epilepsy), as they are outlined in the ''European White Paper on Epilepsy'', which addresses the epidemiology, diagnosis, treatment, living with epilepsy, quality of life, education, research and epilepsy organizations [16]. We used the QOLIE-31 by permission of the copyright holders.

Methods

Translation of QOLIE-31 into Greek

Two physicians, native Greek speakers with fluency in English, performed the translation of the instrument into Greek. A panel of five people, four physicians and a Greek language teacher, discussed the two versions so that a consensus version was agreed upon. Our primary goal was to achieve conceptual equivalence and cultural relevance of the translated items and ensure that the translated instrument was comprehensible to the Greek patients. Five epileptic patients completed the Greek version of the instrument. The lay review involved discussion of two neurologists with these patients, in a group, about the items of the questionnaire [17]. We detected no problems in terms of acceptance or comprehension of the questionnaire content or wording. Finally, an anthropologist, native American-English speaker, who was also fluent in Greek, back-translated the Greek version into English. We did not identify any significant differences between the original and back-translated versions. The layout and the images of the Greek version were identical to the original instrument.

Patients

The patients who participated in the study (N = 63) were outpatients who attended the epilepsy clinics of the Department of Neurology, University of Thrace, in Alexandroupoli, Greece. Their mean age was 33.6 years (range = 17–68). Eligibility criteria were good knowledge of Greek language and the ability to read and write and duration of epilepsy for at least one year. Exclusion criterion was any serious cognitive dysfunction (like dementia or learning disability). All the instruments were self-completed.

Before completing the questionnaire, the patients were interviewed by a neurologist. This interview addressed issues of socio-demographic characteristics, such as age, gender, employment status, level of education, residence (rural or urban) and marital status, as summarized in Table 1. Table 2 shows disease characteristics, such as age of onset, duration, aetiology, type of seizures (patients with more than one seizure types were classified according to the most severe) and seizure frequency. The number of anti-epileptic drugs (AEDs) used, the presence or absence of any side effects from the medication, comorbidity with other diseases and medications (other than AEDs) used, compliance with medication, hospitalization during the past year, their satisfaction from their social life and whether or not their relatives and friends were informed of the disease are also shown in Table 2.

A random subset of patients who reported no change in their health status (N = 11) were re-examined after a period of 2–5 weeks. We chose this period because it has already been proposed by other researchers as being long enough to ensure that the patients did not recall their previous

Table 1. Socio-demographic characteristics of patients

Characteristics	Options	Number of patients	Percentage (%)
Sex	Male	33	52
	Female	30	48
Age	Mean 33.6 (range :17–68)		
Residence	Urban	36	63
	Rural	21	37
Level of education	Primary school	19	33
	Basic high school	22	39
	Advanced school	6	10
	University	10	18
Employment status	Student	10	18
	Employed	29	52
	Unemployed	14	25
	Pensioner	3	5
Marital status	Single	25	44
	Married	26	46
	Divorced	4	7
	Widowed	2	3

answers [18]. This period is also considered short enough to ensure that no major differences had arisen.

General health questionnaire (GHQ-28)

In addition to the QOLIE-31, all patients completed the General Health Questionnaire 28 (GHQ-28), as a criterion measure. The GHQ-28 is a self-completed instrument designed to detect the presence of any psychiatric distress related to general medical illness [19]. It contains 28 items divided into four subscales: somatic symptoms, anxiety/insomnia, social dysfunction and severe depression. The instrument has been translated into Greek and its psychometric properties have been confirmed [20].

Statistical analysis

We carried out all analyses using Stata v. 6 (StataCorp, College Station, TX). We calculated the *internal consistency* of the QOLIE-31 and its subscales using the Cronbach's α coefficient. We analyzed the *test–retest reliability* using the intra-class correlation coefficients and Pearson's coefficient in the subgroup of patients, who were re-examined and who had reported no change in their health or social status during the period that had elapsed.

Table 2. Epilepsy characteristics of patients

Characteristics	Options	Number of patients	Percentage (%)
Age of onset	Mean: 18.6 Range: 1–57 years		
Duration	Mean: 14.9 years		
Aetiology	Idiopathic	17	30
	Secondary /cryptogenic	57	70
Seizure type	Generalized	19	35
	Simple partial	2	4
	Complex partial	14	25
	Secondarily generalized	20	36
Seizure frequency	None in the past year	14	25
	1–2 per year	14	25
	Less than 1 per month	8	14
	1–5 per month	13	23
	More than 5 per month	7	13
Number of AEDs	One	28	48
	More than one	30	52
Side-effects (N = 56)	Present	26	46
Epilepsy- related hospitalli-sation in the past year (N = 57)	Yes	12	21
Compliance with medication (N = 56)	Good	52	93
Information of others about epilepsy (N = 55)	Yes	45	82
Comorbidity with other diseases (N = 56)	Yes	9	16
Medication other than AED used (N = 55)	Yes	10	18

AED: Anti-epileptic drugs.

We assessed the *convergent validity* by comparison of the QOLIE-31 and its subscales with the GHQ global score and comparison of certain subscales with other external measures (e.g., social functioning with satisfaction from social life and medication effects with the presence of side effects).

We evaluated the *discriminative validity* using the method of known-groups comparisons between subgroups of patients who were hypothesized *a priori* to have differences in QoL, according to data from the literature and general knowledge about epilepsy [14, 21–23]. Patients with less frequent

seizures are expected to have better QoL than those with more frequent seizures. Also, those who are employed are expected to have better QoL than the unemployed.

We examined the variation in the QOLIE-31 overall scores between patients with different seizure frequency and employment status, by employing one-way analysis of variance (ANOVA) and Spearman's rank coefficient.

Results

The *internal consistency* for the QOLIE-31 overall score and subscales was high. The Cronbach's α coefficient was 0.92 for the overall score and between 0.59 and 0.83 for each dimension.

We demonstrated the *test–retest reliability*, as indicated in Table 3. We compared the mean scores, the intra-class correlation coefficients and Pearson's product-moment coefficient between the entire patient population and the subgroup who were re-examined. We found no statistically significant differences between mean values in the overall score and sub-scales, except for "seizure worry" and "medication effects". Intra-class correlation coefficients ranged between 0.49 and 0.89 and Pearson's coefficient was between 0.53 and 0.92.

We assessed the *convergent validity* by comparison between the QOLIE-31 scores and GHQ score (Table 4) and found strong agreement between the two questionnaires. Pearson's correlation coefficient was -0.61 ($p < 0.001$) between the GHQ and total QOLIE-31 score and between -0.45 and -0.62 ($p < 0.05$) between the GHQ and the QOLIE-31 dimensions, except for the "medication effects" subscale, for which Pearson's coefficient was -0.20, but it was not statistically significant.

Moreover, we found an association between the "social functioning" subscale score and the degree of the patient's satisfaction with his or her social life, as it was determined during the clinical interview. The examiner asked the patient to rate his or her social life, as satisfactory (1), adequate (2) or not satisfactory (3). Statistical analysis showed a significant negative association between the "social functioning" subscale score and the patient's rating (Spearman's rho was -0.46), ($p = 0.002$). This indicates a parallel relationship between better social life and the QOLIE-31 subscale score.

We compared the "medication effects" subscale scores between the groups of patients who reported side effects from AEDs when asked during the interview (N = 26, mean score = 47.03) and those who did not (N = 30, mean score = 61.48). We found a negative association between the subscale score and the presence of side effects, but the difference was not statistically significant, ($p = 0.076$).

We examined the *discriminative validity* by estimating the difference between the QOLIE-31 overall score of patients with different seizure frequency and different employment status. We found a statistically significant negative association between the QOLIE-31 overall score and frequency of seizures (Spearman's rho = -0.41, $p = 0.002$), indicating that the QOLIE-31 score is reduced as the frequency of epileptic seizures increases, as was hypothesized. Also, we calculated the average overall score for each working category. The mean values showed that the unemployed have a worse QOLIE-31 rating (mean

Table 3. Mean scores and internal consistency of QOLIE-31, mean and mean differences of the QOLIE-31 test and retest scores, and intra-class and Pearson's correlation coefficients

QOLIE-31	Test (N = 63) Mean (SD)	Cronbach's α	Retest (N = 11) Mean (SD)	Difference	ICC	*R*
Total	68.5 (17.2)	0.92	67.6 (21.9)	0.9	0.89	0.92
Seizure worry	50.7 (29.6)	0.83	35.1 (28.0)	15.6	0.49	0.53
Overall QoL	71.5 (17.1)	0.59	66.7 (18.0)	4.8	0.71	0.70
Emotional well-being	70.3 (17.9)	0.69	70.2 (23.2)	0.1	0.65	0.71
Energy/fatigue	67.4 (21.4)	0.77	70.0 (22.7)	−2.6	0.73	0.76
Cognitive functioning	72.5 (22.3)	0.79	73.9 (27.3)	−1.4	0.75	0.78
Medication effects	54.6 (32.1)	0.71	64.8 (22.5)	−10.7	0.65	0.58
Social functioning	72.7 (24.1)	0.77	75.6 (27.7)	−2.36	0.87	0.89

SD = standard deviation, ICC = intra-class correlation.

Table 4. Correlation coefficients[a] between QOLIE-31 and GHQ

QOLIE-31	Total	SW	OQL	EWB	E/F	COG	ME	SF	GHQ
Total	–								
Seizure Worry	0.56[b]	–							
Overall Quality of life	0.68[b]	0.44[b]	–						
Emotional well-being	0.86[b]	0.46[b]	0.67[b]	–					
Energy/fatigue	0.76[b]	0.21	0.57[b]	0.71[b]	–				
Cognitive functioning	0.85[b]	0.30[c]	0.45[b]	0.70[b]	0.62[b]	–			
Medication effects	0.50[b]	0.47[b]	0.30[c]	0.32[c]	0.24	0.30[c]	–		
Social functioning	0.84[b]	0.45[b]	0.55[b]	0.65[b]	0.57[b]	0.65[b]	0.45[b]	–	
GHQ									
Total	−0.61[b]	−0.46[b]	−0.59[b]	−0.58[b]	−0.62[b]	−0.45[c]	−0.20	−0.48[c]	–

[a]Pearson correlation coefficients.
[b]$p < 0.001$.
[c]$p < 0.05$.
SW: seizure worry, QOL: overall quality of life, EWB: emotional well-being, E/F: energy/fatigue, COG: cognitive functioning, ME: medication effects, SF: social functioning, GHQ: general health questionnaire.

score = 57.9) than the other groups: employed (68.2), pensioners (74.5) or students (75.2), but the difference was not statistically significant.

Discussion

The Greek version of the QOLIE-31 inventory exhibits psychometric properties equivalent to those of the original American-English version, [10], and those of the German and the Spanish versions [7, 8]. Therefore, the authors believe it is a valid and reliable measure of quality of life for use in the Greek epileptic patients.

In our study, the *internal consistency* was high for the total score (Cronbach's $\alpha = 0.92$) and most sub-scales (Cronbach's $\alpha = 0.59$–0.83). Alpha coefficients of a magnitude of 0.70 or greater are considered indicative of adequate scale reliability, at the level of group comparisons [24]. Cronbach's α coefficient was >70 for each dimension, except "emotional well being" (coefficient $\alpha = 0.69$) and "overall QoL" (coefficient $\alpha = 0.59$). For the overall QoL scale, the Spanish version had a similar low coefficient α (0.55) and its authors suggested that this might be because of to the small number of items (only two) in the sub-scale, which influences the alpha coefficient's value [8]. They also suggested that perhaps this problem could be resolved by adding more items to this subscale. However, by adding more questions, the instrument becomes lengthier and thus less practical. We believe the simplicity and easy completion of the instrument is its great advantage, and further studies are needed in order to evaluate the cost and benefit of adding items.

We have shown the *test–retest reliability* of the questionnaire by high intra-class coefficients and Pearson's correlation coefficients in patients who were re-examined. The Pearson's coefficient was not satisfactory for every sub-scale (e.g. for the "seizure worry" scale it was 0.53). This might be because of the small re-test sample.

The product-moment correlation and intra-class correlation coefficients for the "seizure worry" and "medication effects" subscales were below the standard of 0.70. The mean score in these two subscales in our patients was lower than that reported in American, Spanish, and French patients, although in every other subscale our patients had higher average scores, as Table 5 shows [7–10]. Perhaps this difference could be attributed to the lack of extensive and detailed patient education regarding various aspects of epilepsy or its' medications. A campaign aiming at providing better public understanding of epilepsy would be helpful in this direction and should become a health priority among governments and health authorities in Greece.

We demonstrated the *convergent validity* by the high correlation between the QOLIE-31 and GHQ-28 ($r = -0.61$), with stronger correlations between the GHQ and the dimensions of QOLIE-31 mostly

Table 5. Mean scores and internal consistency of the QOLIE-31 in the Greek, American, Spanish and French studies

	Greek		American		Spanish		French	
	Mean score (SD)	Cronbach's α	Mean score (SD)	Cronbach's α	Mean score (SD)	Cronbach's α	Mean score (SD)	Cronbach's α
Total	68.5 (17.2)	0.92	63 (16)	0.93	61.8 (17.3)	0.92	61.9 (19)	0.86
Seizure worry	50.7 (29.6)	0.83	58 (26)	0.79	51.5 (29.8)	0.83	58.7 (30.1)	0.84
Overall QoL	71.5 (17.1)	0.59	67 (18)	0.79	63.8 (16.9)	0.55	64 (21.1)	0.83
Emotional well-being	70.3 (17.9)	0.69	67 (19)	0.83	61.8 (19.1)	0.77	57.6 (20.6)	0.83
Energy/ fatigue	67.4 (21.4)	0.77	55 (21)	0.84	60.1 (20.2)	0.77	51.7 (19.8)	0.82
Cognitive functioning	72.5 (22.3)	0.79	60 (23)	0.85	60.3 (23.8)	0.82	61.7 (25.4)	0.82
Medication effects	54.1 (32.1)	0.71	55 (31)	0.78	60.3 (29.1)	0.77	65.5 (30.1)	0.85
Social functioning	72.7 (24.1)	0.77	67 (27)	0.77	66.4 (28)	0.77	69.4 (26.4)	0.82

SD = standard deviation.

related to "psychic health", namely overall quality of life, emotional well-being and energy/fatigue. Moreover, we supported the *convergent validity* by the finding that the "medication effects" score is lower in patients reporting adverse effects than in those who do not and the "social functioning" score is lower in patients who report dissatisfaction from their social lives. The differences were not statistically significant, which may be due to the small number of patients in our sample.

We evaluated the *discriminative validity* by showing the difference in QOLIE-31 scores between patients with different seizure frequencies. This hypothesis has already been confirmed in various studies [14, 21–23].

We did not examine the sensitivity of the Greek version to clinical change. However, this sensitivity has already been demonstrated for the Spanish and the German versions [7, 8]. Since the Greek version has shown psychometric properties similar to these and the original English versions, we assume that sensitivity is a feature of the instrument.

In addition to the 31 questions in the QOLIE-31 inventory, there is a free space at the end, where patients can write any personal comments. Although such information, probably, cannot be used for comparison in clinical studies, it might be of importance in evaluating the individual patient and gaining a better understanding of the patient's QoL-related concerns. Patients' comments referred to problems such as stigma, restrictions in work, alcohol use, driving, swimming and their wish of being seizure-free.

In summary, we have demonstrated the validity and reliability of the QOLIE-31 adaptation to the Greek population by showing high internal consistency, construct validity and temporal stability. Thus, the Greek version might prove useful in clinical trials on Greek patients with epilepsy, and it would enable Greek neurologists to participate in international studies.

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