Validation of the Subjective Handicap of Epilepsy (SHE) in Brazilian patients with epilepsy

EPILEPSY & BEHAVIOR, SAN DIEGO, v. 24, n. 3, pp. 345-351, JUL, 2012
http://www.producao.usp.br/handle/BDPI/35127

Epilepsy & Behavior 24 (2012) 345–351

Contents lists available at SciVerse ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Validation of the Subjective Handicap of Epilepsy (SHE) in Brazilian patients with epilepsy

Edna de Almeida Monteiro [a], Flávia de Lima Osório [a,b,*], Alexandre Veriano Junior [a], Roberto Souza Molina [a], Sandra Souza Funayama [a], Vera Cristina Terra [a], Tonicarlo R. Velasco [a], Ricardo Guarnieri [a], Marino Bianchin [a], João Alberto Assirati Jr. [a], Americo Ceiki Sakamoto [a], Jaime Eduardo Cecílio Hallak [a,b]

[a] Department of Neuroscience and Behavior, Medical School of Ribeirão Preto, University of São Paulo, Avenida dos Bandeirantes 3900, CEP 14048-900, Ribeirão Preto, São Paulo, Brazil
[b] INCT, Medicina Translacional, Avenida dos Bandeirantes 3900, CEP 14048-900, Ribeirão Preto, São Paulo, Brazil

ARTICLE INFO

Article history:
Received 28 January 2012
Revised 9 April 2012
Accepted 21 April 2012
Available online 30 May 2012

Keywords:
Epilepsy
Quality of life
Instrument
Validation
Transcultural
Subjective handicap of epilepsy

ABSTRACT

The objectives of the study were to translate and adapt the Subjective Handicap of Epilepsy (SHE) instrument to Brazilian Portuguese and to determine its psychometric properties for the evaluation of quality of life in patients with epilepsy. A sample of 448 adult patients with epilepsy with different clinical profiles (investigation, preoperative period, postoperative period, and drug treatment follow-up) was evaluated with the SHE and the Epilepsy Surgery Inventory (ESI-55). Exploratory factorial analysis demonstrated that four factors explained 60.47% of the variance and were sensitive to discriminate the different clinical groups, with the preoperative group having the poorest quality of life. Internal consistency ranged from 0.92 to 0.96, and concurrent validity with the ESI-55 was moderate/strong (0.32–0.70). Test–retest reliability was confirmed, with an ICC value of 0.54 (2 days), 0.91 (7 days), and 0.97 (30 days). The SHE had satisfactory psychometric qualities for use in the Brazilian population, similar to those of the original version. The instrument seems to be more adequate in psychometric terms for the postoperative and drug treatment follow-up groups, and its use should be encouraged.

1. Introduction

Epilepsy is a chronic neurological disease characterized by recurrent unprovoked epileptic seizures. The disease affects about 50 million people worldwide, with an estimated prevalence of 200–700/100,000 inhabitants across all age ranges [1].

The disease can be treated with drugs (first line) or surgery, given that around 30% of the patients have seizures that are refractory to medications. Epilepsy is associated with high rates of limitation, disability, and functional losses with a negative impact on quality of life (QOL). The impossibility to predict when and where seizures will occur may generate permanent states of anxiety which patients respond to with important restrictions in daily life. The condition often places patients in a position of social exclusion and causes occupational problems, in addition to the direct losses related to seizures and medication side effects [2].

Many studies on health-related QOL (HRQOL) in epilepsy are limited to the analysis of the frequency of seizures as a predictive factor of QOL improvement. Quality of life is currently understood as one's perceptions within the framework of values of his culture, including expectations, standards and interests, physical and psychological health, level of independence, sociability, and relations with the environment [3–6].

Because there is no single concept to designate what we understand as QOL, there are different instruments to assess it. The most frequently used today are the versions of the Quality of Life in Epilepsy scales QOLIE-89, QOLIE-31, and QOLIE-10, the Washington Psychosocial Seizure Inventory (WPSI), and the Side Effect and Life Satisfaction (SELS) scale, which comprise generic and specific measures of QOL and are used all over the world.

Health-related QOL has been recently evaluated before and after surgery for epilepsy since the current view is that the success of surgery is not simply related to seizure control, but also to psychosocial well-being, occupational status, leisure, and subjective life aspects. Among the instruments that evaluate HRQOL, particularly important are the Epilepsy Surgery Inventory (ESI-55) and the Subjective Handicap of Epilepsy (SHE).

No ideal measure of QOL related to epilepsy has arisen, and it is still necessary to perform psychometric studies of all currently available instruments in order to refine their adequacy. For the Brazilian population, in particular, the instruments available are the ESI-55, validated by Alonso et al. [7], and the QOLIE-31, validated by da Silva et al. [8]. Therefore, in this study, our focus was placed on the SHE.

* Corresponding author at: Department of Neuroscience and Behavior, Medical School of Ribeirão Preto, University of São Paulo, Avenida dos Bandeirantes 3900, CEP 14048-900, Ribeirão Preto, São Paulo, Brazil.
E-mail address: flaliosorio@ig.com.br (F.L. Osório).

1525-5050/$ – see front matter © 2012 Elsevier Inc. All rights reserved.
doi:10.1016/j.yebeh.2012.04.129

The SHE was developed by O'Donoghue et al. [9] at the London National Hospital for Neurology and Neurosurgery based on a literature review and on interviews with patients and specialists in the area in order to identify the key problems that affect the lives of epilepsy patients. The instrument contains 32 questions divided into six QOL domains: 'work and activities' (eight items), 'social and personal' (four items), 'physical' (four items), 'self-perception' (five items), 'satisfaction with life' (four items), and 'change' (seven items). The items are scored on a Likert scale with values ranging from 1 to 5. In the original psychometric study, the SHE showed adequate construct validity and satisfactory internal consistency in the six domains, ranging from 0.80 to 0.90. Test–retest reliability was also adequate, ranging from 0.69 to 92 for intervals of 24 h, 1 week and 4–8 weeks. It also had adequate predictive validity, with sensitivity for the benefits of successful surgery for QOL.

In view of the adequate psychometric properties of the SHE, its rapid application and easy scoring, and the scarcity of instruments that evaluate QOL in the population with epilepsy, the objectives of the present study were to translate and adapt the SHE to Brazilian Portuguese and to determine its psychometric properties as a specific instrument for the evaluation of QOL among Brazilian subjects with epilepsy in clinical and surgical follow-up.

2. Methods

The study consisted of four phases. Phase 1 consisted of the translation and transcultural adaptation of the SHE. The objective of phases 2 and 3 was to determine the construct validity of the scale using factorial analysis and its internal consistency, discriminant validity (phase 2), and concurrent validity (phase 3). Phase 4 examined the test–retest reliability of the instrument.

2.1. Translation and adaptation of the SHE to Brazilian Portuguese

The process of translation of the SHE was based on the recommendations of Guillemin [10] and the Scientific Advisory Committee of the Medical Outcomes Trust [11]. The instrument was first translated by an English-speaking professional who was aware of the objectives of the study. This version was analyzed by the multidisciplinary team of a center for the treatment of epilepsy that suggested small modifications in order to improve the semantic, cultural, conceptual, and idiomatic equivalence of the translated instrument. This final version was then back-translated by a bilingual translator who had no access to the original English version and sent to the authors of the original instrument, who considered it to be adequate.

2.2. Subjects

The subjects of the samples studied in phases 2, 3, and 4 were recruited in the Epilepsy Surgery Center (CIREP, in the Portuguese acronym) of the Ribeirão Preto Medical School University Hospital, which provides inpatient and outpatient care for about 2000 epilepsy patients from the whole country. The sample was selected by convenience, and the composition of each phase is described in detail below.

Phase 2 206 patients under preoperative evaluation due to signs and symptoms of epilepsy of difficult pharmacological control ('Pre' group), 120 patients in clinical follow-up one year after surgical intervention for the treatment of epilepsy ('Post' group), and 46 patients with medication-controlled epilepsy (control group).

Phase 3 38 subjects admitted to CIREP for diagnostic investigation.

Phase 4 38 subjects admitted to CIREP for diagnostic investigation ('DI' group); 16 outpatients with epileptic seizures of difficult pharmacological control ('DC' group), and 24 subjects with epilepsy controlled with drugs ('C' group).

All subjects gave written informed consent to participate in the study. Inclusion criteria were: being under follow-up at CIREP, age of 18 years or more, and minimum education of two years. Exclusion criteria were: presence of Axis I psychiatric disorders (DSM-IV), mental retardation detected by previous neuropsychological evaluation, clinical or laboratory signs of intoxication by antiepileptic drugs detected by neurological evaluation, and occurrence of a seizure during the application of the questionnaires.

2.3. Instruments

a. *Subjective Handicap of Epilepsy* (*SHE*) — proposed by O'Donoghue et al. [9] and translated and adapted to Brazilian Portuguese as part of the present study. It is an instrument consisting of 32 items scored on a five-point Likert scale whose objective is to assess the QOL of patients with epilepsy.
b. *Epilepsy Surgery Inventory* (*ESI-55*) — proposed by Vickrey et al. [12] and translated and validated for Brazilian Portuguese by Alonso et al. [7]. It is an instrument consisting of 55 questions whose objective is to assess the QOL of patients with epilepsy, divided into the following 11 domains: general health status, functional capacity, limitation due to physical aspects, limitation due to emotional aspects, social aspects, pain, mental health, vitality, cognitive aspects, limitation due to cognitive aspects, and overall QOL.

2.4. Data collection

The study was evaluated and approved by the local research ethics committee (Protocol HCRP No. 3607/2006).

The instruments were applied by one of the investigators who is also a member of CIREP. For outpatients, the instruments were applied during the social work evaluation, which is part of the clinical protocol of CIREP. For hospitalized patients, the instruments were applied at the ward. The time needed to fill out the instruments ranged from 20 to 60 min.

Data regarding the sociodemographic and clinical characteristics of the samples were obtained from the medical records and from the clinical evaluation protocol.

Different intervals were used for the retest of the three groups of patients: 48 h for the DI group, 7 days for the DC group, and 30 days for the C group. The instrument was completed again during hospitalization or routine follow-up consultation.

2.5. Data analysis

The data were stored in a data bank and analyzed using the SAS software, version 9, with the level of significance set at $p<0.05$.

The sociodemographic and clinical characteristics of the sample were analyzed with descriptive and parametric statistical tests (ANOVA followed by Tukey's post-hoc test for quantitative variables and the chi-square test for qualitative variables).

The following parameters of the SHE were analyzed:

- Construct validity — factorial structure: exploratory factorial analysis using principal component analysis with varimax rotation in order to assess the internal consistency and construct validity of the scales. The criteria used for factor composition were: Kaiser–Meyer–Olkin (KMO) index above 0.60; significant Bartlett's sphericity test, eigenvalues above 1; percent variance explained by the factors of about 60%; and minimum factorial load of approximately 0.40;
- Internal consistency: Cronbach's alpha, with values above 0.60 considered acceptable [13];
- Concurrent validity: Spearman correlation coefficient, with correlation values of 0 indicating no association, 0.1 to 0.2 indicating mild association, 0.3 to 0.5 indicating moderate association, 0.6 to 0.8 indicating strong association, and >0.8 indicating total association [14];

– Discriminant validity: correspondence maps and linear mixed-effects model, with the dimensions presented in the map's axes corresponding to the percentage of variance explained by each axis [15];

For the determination of the test–retest reliability, the intraclass correlation coefficient (ICC) with a confidence interval (CI) of 95% was used for each item, with values of 0–0.20 considered negligible, values of 0.21–0.40 as mildly, values of 0.41–0.60 as moderately, values of 0.61–0.80 as substantially, and values >0.81 as highly adequate [16].

3. Results

3.1. Translation and adaptation of the SHE (phase 1)

The Brazilian-Portuguese version of the SHE is available upon request to the authors.

3.2. Subjects

The sample of phase 2 consisted of 372 subjects divided into three groups according to clinical profile, the same occurring for phase 4 subjects (n = 78), whereas phase 3 subjects (N = 38) were all under diagnostic evaluation. The sociodemographic characteristics of these samples are presented in Table 1.

Table 1 shows that the subjects of the three phases had closely similar sociodemographic profiles. The subjects were proportionately distributed in terms of sex, and the mean sample age was 31–38.5 years. Regarding education, most subjects had only completed elementary school. In respect to work, there was a predominance of subjects on leave for health reasons, retired, or without paid occupational activities. Statistical analyses revealed no differences between groups regarding the variables studied ($p > 0.05$).

3.3. Psychometric study

3.3.1. Construct validity: factorial analysis, internal consistency and discriminant validity (phase 2)

After analysis of the KMO index and of Bartlett's test of sphericity, the sample was considered to be adequate for the study of the factorial structure of the SHE.

Exploratory analysis according to Kaiser's criteria indicated the presence of four factors that together explained 60.47% of data variance.

Table 2
Distribution of the SHE items as a function of the domains of the original study and the factors obtained (N = 372).

Item	SHE domains	Factor 1	Factor 2	Factor 3	Factor 4
1	Work and activity	0.66			
2	Work and activity	0.64			
3	Work and activity	0.56			
6	Work and activity	0.66			
14	Work and activity	0.76			
15	Work and activity	0.71			
19	Work and activity	0.64			
20	Work and activity	0.71			
26	Change		0.73		
27	Change		0.69		
28	Change		0.70		
29	Change		0.68		
30	Change		0.78		
31	Change		0.78		
32	Change		0.75		
21	Self-perception	0.62			
22	Self-perception	0.59			
23	Self-perception	0.61			
24	Self-perception	0.67			
25	Self-perception	0.70			
8	Social and personal			0.54	
9	Social and personal			0.53	
10	Social and personal			0.55	
11	Social and personal			0.64	
4	Physical				0.70
5	Physical				0.66
17	Physical				0.48
18	Physical				0.37
7	Satisfaction with life			0.63	
12	Satisfaction with life			0.50	
13	Satisfaction with life			0.70	
16	Satisfaction with life			0.60	

Table 2 presents the distribution of the items of the SHE and of their factorial loads on each of the factors detected.

Table 2 shows that the distribution of the items in the factorial structure of the Brazilian version of the SHE for this sample was similar to that of the original study [9], which detected six factors. Factor 1 explained 45.66% of the variance and consisted of the items related to self-perception and work/activities of the original study. Factor 2 explained 6.42% of the variance and consisted of the items in the 'change' domain. Factor 3, comprising the items of the 'social/personal' and 'satisfaction with life' domains, explained 5.19% of the

Table 1
Sociodemographic characterization of the sample as a function of the different groups of subjects.

	Subjects — phase 2						Subjects — phase 3		Subjects — phase 4					
	Pre (N = 206)		Post (N = 120)		Control (N = 46)		Total (N = 38)		DI (N = 38)		DC (N = 16)		C (N = 24)	
	x	SD	x	SD	x	SD	x	SD	x	SD	x	SD	x	SD
Age (years)	36.53	8.49	36.96	8.90	31.00	11.43	36.89	9.49	36.89	9.49	38.6	10.3	38.5	9.2
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Sex														
Female	103	50.0	63	52.5	18	39.1	20	52.6	20	52.6	8	50	14	58
Male	103	50.0	57	47.5	28	60.9	18	47.4	18	47.4	8	50	10	42
Work*														
1	62	30.1	43	35.8	26	56.5	11	28.9	11	28.9	4	25	9	38
2	10	4.8	9	7.5	6	13.0	2	5.3	2	5.3	2	12	1	4
3	134	65.1	68	56.7	14	30.4	25	65.8	25	65.8	10	63	14	58
Schooling														
Elementary	137	66.5	78	65.6	25	54.4	18	47.4	18	47.4	5	31	14	58
High school	49	23.8	26	21.8	19	41.3	9	23.7	9	23.7	7	44	7	29
Higher education	20	9.7	15	12.6	2	4.4	11	28.9	11	28.9	4	25	3	13

DI = subjects hospitalized for diagnostic investigation; DC = subjects with epilepsy of difficult control with medications; C = subjects with epilepsy controlled with drugs.
* (1) Individuals with regular remunerated occupational activities; (2) individuals who are studying or training; (3) retired individuals on leave through the INSS or individuals with no remunerated occupational activities.

Table 3
Cronbach's alpha coefficient for the Pre, Post and Control groups and the total sample of phase 2 as a function of the different domains of the scale.

Domains	Groups			
	Pre (N = 206)	Post (N = 120)	Control (N = 46)	Total (N = 372)
Work and activity	0.87	0.89	0.86	0.92
Social and personal	0.79	0.80	0.73	0.82
Physical	0.60	0.64	0.72	0.72
Self-perception	0.78	0.82	0.79	0.87
Satisfaction with life	0.66	0.80	0.72	0.74
Change	0.85	0.87	0.90	0.91
General	0.93	0.95	0.92	0.96

variance, and factor 4, consisting of the items in the 'physical' domain, explained 3.2% of the data variance.

Regarding the internal consistency of the scale, quite expressive alpha values were found both for the total scale (0.92–0.96) and for the different domains (0.60–0.92), considering the different samples of phase 2. These findings, presented in Table 3, indicate coherence of the scale as a whole and of its domains, regardless of the sample used.

It should be pointed out that the internal consistency analysis for the individual items indicated that all items significantly contributed to increasing the consistency of the SHE since the exclusion of any item would cause a reduction of the alpha values.

Regarding discriminant validity, the joint analysis of the three different samples of phase 2 (total sample) through correspondence maps (Fig. 1) indicated that it was not possible to discriminate levels 3 ("*at times*") and 4 ("*rarely*") of the Likert scale, whereas the more extreme levels 1, 2, and 5 were reasonably distanced, indicating the discriminative capacity of the instrument.

When considering the samples separately, there was a clearly low concentration of marks close to the more favorable level of the scale (level 5) in the Pre group, indicating that these patients, possibly more symptomatic, had a lower QOL. Analysis of the Post and control groups demonstrated a greater concentration of marks in the higher levels of the Likert scale, indicating a better QOL for these less symptomatic patients as a function of surgery or of pharmacological control.

Another aspect related to the discriminative capacity of the SHE was the comparison of the different domains of the SHE and the scores of the different sample groups using the mixed-effects linear model. The results are shown in Fig. 2.

As seen in Fig. 2, regarding the domains 'work and activities', 'physical', 'satisfaction', and 'social and personal', there were significant

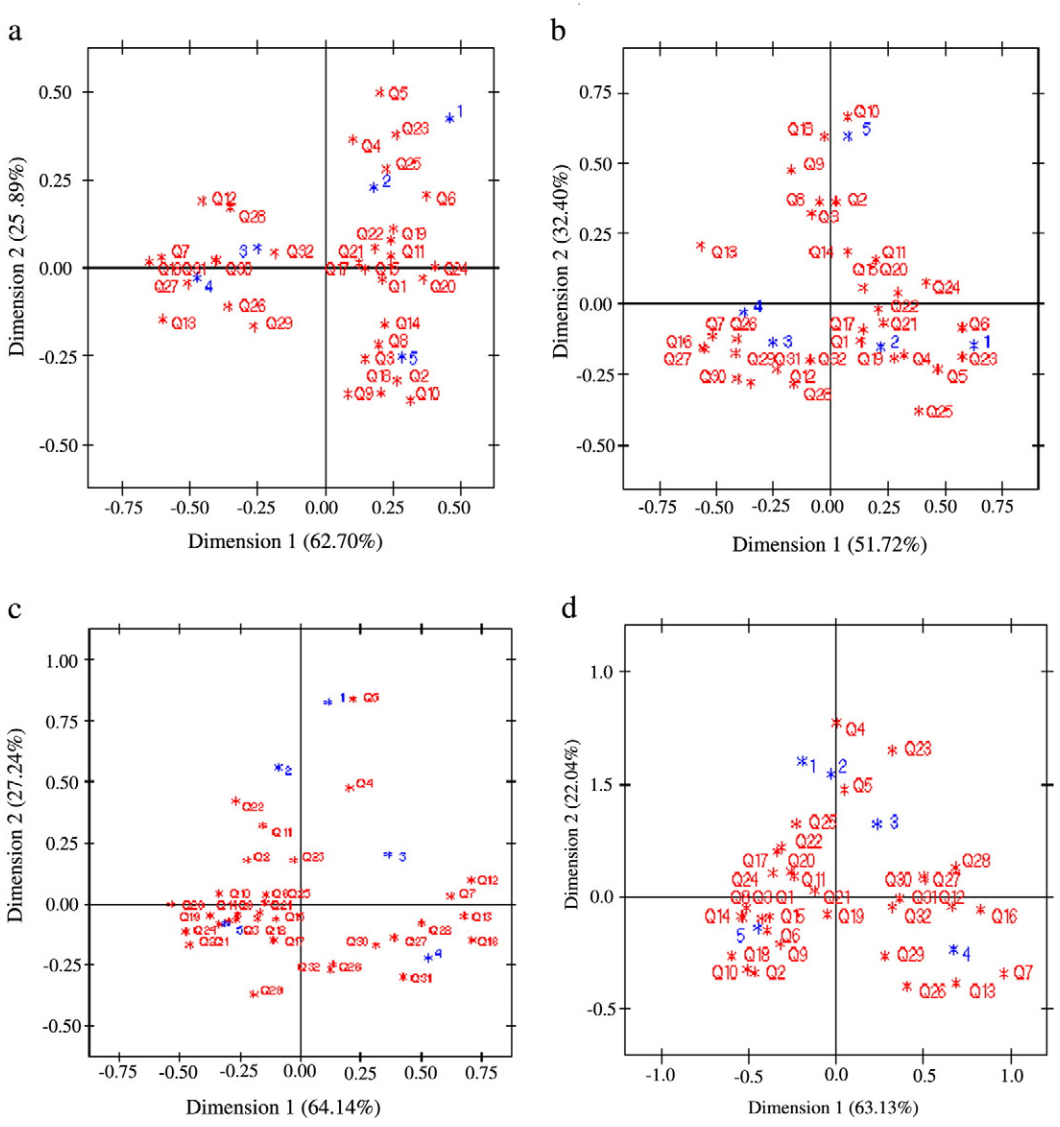

Fig. 1. Correspondence maps for the total sample (a), the Pre group (b), the Post group (c), and the Control group (d).

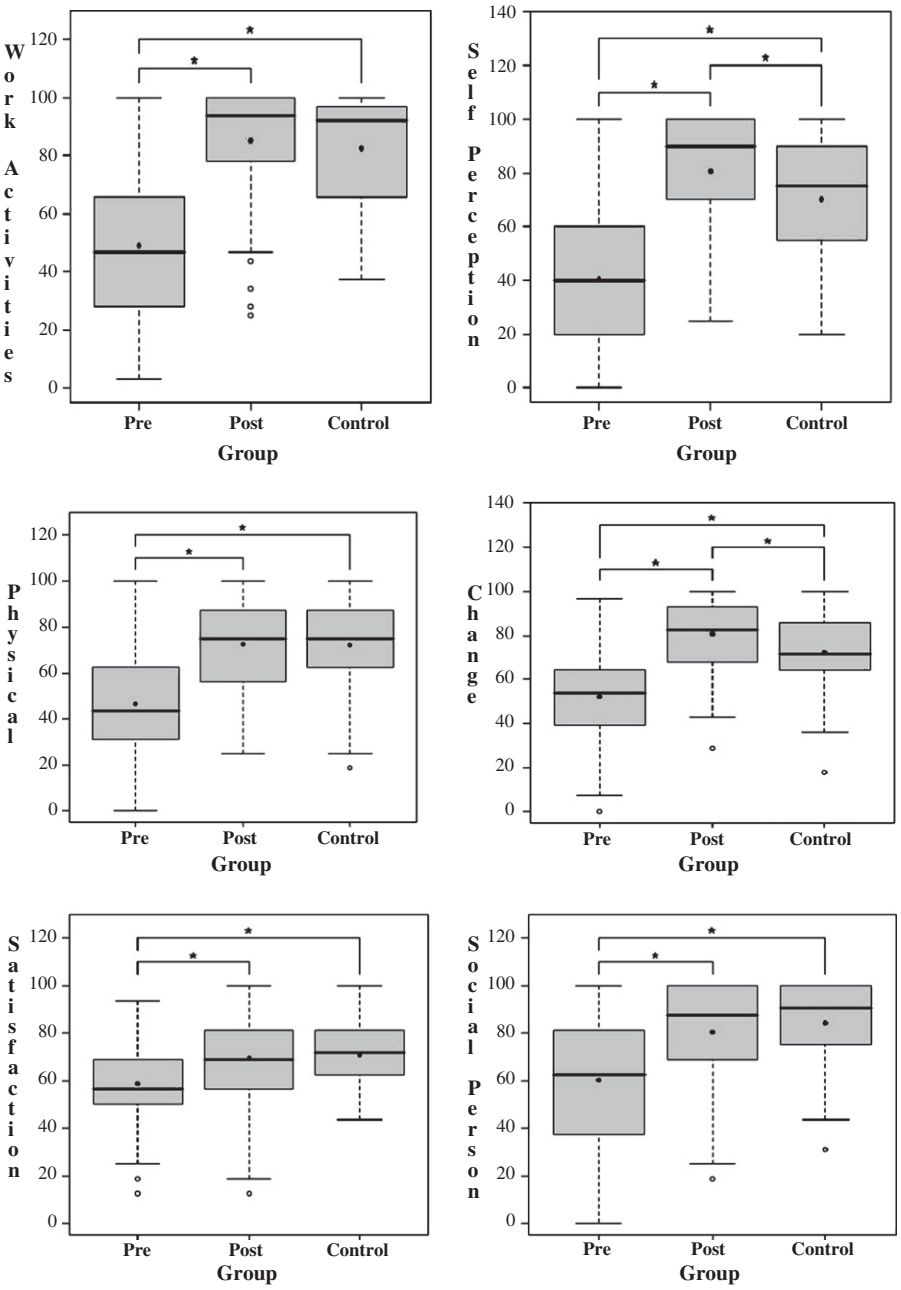

Fig. 2. Box plot representing the different domains of the SHE, with emphasis on the difference (*p<0.05) between the Pre group and the Post and Control groups.

differences between the Pre and Post groups and between the Pre and control groups, with the Pre group having the lowest scores, i.e., the lowest QOL. No differences were detected between the Post and control groups regarding these domains. In contrast, for the self-perception and change domains, there were significant differences between the Pre and Post groups and the Pre and control groups, with the subjects in the Pre group having a lower score than all others, and between the Post and control groups, with the Post group having a higher score in these domains.

3.3.2. Construct validity: concurrent validity (phase 3)

The concurrent validity of the SHE was evaluated by correlation with the ESI-55, an instrument already validated that evaluates the QOL of patients with epilepsy. Table 4 presents the values obtained by correlating each subscale of the two instruments.

As shown in Table 4, the statistically significant correlations varied from 0.32 to 0.70, classified as moderate/strong. The most expressive correlations of the different subscales of the SHE occurred with the subscales 'general health status' and 'mental health' of the ESI-55. In addition, the 'work and activity' domain of the SHE was also strongly correlated with the 'social aspects' and 'cognitive aspects' domains of the ESI-55. In turn, the 'physical' domain of the SHE was considerably correlated with the 'cognitive aspects' and 'limitations by physical aspects' domains of the ESI-55, and the 'self-perception' correlated with the 'social aspects' and 'limitations by emotional aspects' of the ESI-55. The 'satisfaction with life' and 'changes' domains showed the lowest number of correlations, which were also a little less expressive.

3.3.3. Test–retest reliability (phase 4)

As described previously, reliability was analyzed separately for each group of phase 4 and at different times. For the DI group, the

Table 4
Correlation between the domains of the SHE and ESI-55 (N = 38).

	SHE					
ESI-55	Work/ activity	Social/ personal	Physical	Self-perception	Satisfaction with life	Changes
GHS	**0.53***	**0.55***	**0.39***	**0.51***	**0.41***	**0.32***
FC	0.17	0.23	0.31	**0.35***	0.11	0.06
LPA	**0.40**	0.22	**0.56***	**0.43***	0.30	**0.41***
LEA	**0.45***	**0.62***	0.33	**0.54***	**0.37***	0.18
SA	**0.50***	**0.71***	**0.40***	**0.60***	0.25	**0.50***
Pain	**0.32***	**0.47***	**0.46***	**0.33***	0.25	0.17
MH	**0.44***	**0.64***	**0.41***	**0.46***	**0.43***	**0.38**
V	0.28	**0.33***	**0.44***	0.31	0.23	**0.33***
CA	**0.49***	**0.65***	**0.66***	**0.41***	0.22	0.19
LCA	0.3	0.28	**0.52***	0.22	0.16	0.24
OQL	**0.45***	**0.57***	**0.53***	**0.41***	0.21	0.27

General health status (GHS); functional capacity (FC); limitation due to physical aspects (LPA); limitation due to emotional aspects (LEA); social aspects (SA); pain; mental health (MH); vitality (V); cognitive aspects (CA); limitation due to cognitive aspects (LCA); overall quality of life (OQL). Bold refers to statistical significance values.
* $p<0.05$ significance.

retest was performed two days after the first application, and the ICC detected for the total scale was 0.54 (IC = 0.28–0.74), classified as moderate. For the DC group, the ICC was 0.91 (IC = 0.77–0.97), classified as highly adequate, with a seven-day interval between applications. For the C group, whose evaluations were performed with an interval of 30 days, the ICC was 0.97 (IC = 0.93–0.98). Table 5 presents the ICC values obtained for the total scale and the subscales.

4. Discussion

In view of the limited availability of instruments and their previous psychometric studies, the present investigation was carried out in order to validate and adapt the SHE for the Brazilian context.

The process of translation and adaptation of the instrument was based on criteria previously described in the literature [7], including appreciation and approval by the authors of the original instrument in order to guarantee its adequacy.

The choice of the SHE among the other instruments available in the international literature was due to its advantages, such as a smaller number of items, a simple and homogeneous scoring system, and its specific evaluation of QOL in the pre- and postoperative context. The sample used consisted of patients with different clinical profiles seen at a center for the treatment of epilepsy. Data were collected in person to enhance reliability.

The sample groups used in the different phases of the study were large, so that the different clinical profiles could be covered in order to favor a broader study of the validity of the SHE as a function of this diversity. However, an attempt was made to control the impact of sociodemographic variables, such as age, sex, and education, to ensure greater homogeneity regarding these aspects.

In respect to the study of construct validity, the analysis of the factorial structure of the SHE in the total patient sample, including those in the Pre, Post, and control conditions, indicated the presence of four factors. Factor 1 explained most of the variance of the data and consisted of the association of the 'work/activity' and 'self-perception' domains, indicating that these two aspects have a more direct relation to the findings of the original study. This result agrees with the guidelines of the World Health Organization (WHO), which has pointed out the need for studies on QOL considering occupational activity and work as relevant aspects for personal and social well-being [17–19].

Similarly, factor 3 consisted of the association of the 'social/personal' and 'satisfaction with life' domains, indicating a more specific association between these aspects. The remaining factors consisted of the same items as those of the original study [9], each representing one of the remaining domains.

These findings indicate the pertinence of the domains proposed and the adequate construct validity of the instrument regardless of the sociocultural context studied.

The internal consistency values of the SHE were also quite satisfactory both for the scale as a whole and for each domain in particular, supporting the construct validity of the scale since the items and domains showed high coherence with one another, regardless of the sample and of the context, and the alpha values obtained in the original study were very close to those of the present investigation [9].

Regarding the discriminant validity, the analysis of correspondence graphs indicated that there was a greater concentration of replies around points 1 ("*very frequently*"), 2 ("*frequently*"), and 5 ("*never*", "*very unhappy*", "*much worse*", "*I don't need help*", "*not a bit*") for the group as a whole. Conversely, the replies to points 3 and 4 ("*at times*" and "*rarely*") did not differ, demonstrating that these points and their denominations can be interpreted as synonyms or may involve subjective concepts. This hampers the interpretation of the data since the same concept may have different meanings for each individual. Considering the predominance of replies in the extremities of the scale, we may hypothesize that a scale with three levels of evaluation might determine QOL with more precision, especially because this is a population with important cognitive impairments, such as memory and concentration deficits. Another factor that may have contributed to the imprecision of the results was the low education of the samples studied, in contrast to the populations studied in developed countries. On the other hand, it should be taken into account that this modification can introduce floor and ceiling effects and reduce sensitivity.

Separate analyses for each subgroup demonstrated little discrimination regarding points 3 and 4 also for the Pre group. However, in this group, there was a clearly lower concentration of replies in point 5, an expected result since a lower QOL could be anticipated for this group due to its clinical profile. The contrary was observed when the Post and control groups were evaluated, i.e., a lower concentration of responses around points 1 and 2 and a greater concentration around point 5. This finding may be related to the well-being of these groups of patients who, with absent or infrequent symptoms, have a better QOL and are more able to reflect when systematically assessing their condition while completing the instrument [20,21].

These findings support the discriminant capacity of the SHE, as well as its potential as a predictive instrument, favoring its use in clinical studies and assays, especially those evaluating the impact of interventions on the treatment of epilepsy.

Analyses using linear mixed-effects model strongly supported the discriminant capacity of the SHE and of its different domains. This analysis showed that the score for subjects in the Pre group was lower than that for the Post and control subjects, as reported in the literature, supporting the negative impact of the symptoms on QOL [22–25]. On the other hand, Post and control subjects differed only regarding the 'self-perception' and 'change' domains, with the Pre group scoring higher than the control group, which indicates a greater influence of surgery on these domains [4,5,25]. O'Donoghue et al. [9] determined the discriminant validity of the SHE by evaluating the benefits of epilepsy surgery in a cohort of patients, with results similar to those obtained here.

Table 5
Intraclass correlation coefficient for the scale in the different samples.

	DI group (2 days)		DC group (7 days)		C group (30 days)	
	ICC	95%CI	ICC	95%CI	ICC	95%CI
Total	0.54	0.28–0.74	0.91	0.77–0.97	0.97	0.93–0.98
Work/activity	0.62	0.38–0.78	0.88	0.69–0.96	0.97	0.92–0.99
Change	0.48	0.19–0.69	0.88	0.70–0.96	0.91	0.79–0.96
Self-perception	0.35	0.04–0.60	0.76	0.43–0.91	0.91	0.86–0.97
Social/personal	0.24	0.08–0.52	0.90	0.74–0.96	0.83	0.64–0.92
Physical	0.65	0.42–0.80	0.61	0.17–0.84	0.81	0.60–0.91
Satisfaction with life	0.52	0.24–0.72	0.86	0.64–0.95	0.89	0.76–0.95

The ESI-55 was used as a comparison parameter to determine the concurrent validity of the SHE. The correlations calculated between these two instruments were considered moderate/strong, ranging from 0.32 to 0.70, values slightly higher than those of the original study (0.21–0.68) [9], suggesting a significant association between the instruments and the concurrent validity of the SHE. The strongest correlations were found between the domains of the SHE and ESI-55 that evaluate the same aspects, e.g., the 'social/personal' domain of the SHE and the 'social aspects' domain of the ESI-55, with a correlation of 0.70 further supporting the concurrent validity. This specific correlation between domains was also demonstrated in the study of O'Donoghue et al. [9]. Nonetheless, important associations were also found between correlate domains, such as the 'limitation due to physical aspects' of the ESI-55 and the 'work/activity' domain of the SHE (0.40). The 'changes' and 'satisfaction with life' domains of the SHE were the ones that least correlated with the different domains of the ESI-55. This is noteworthy, given that the impact of the different changes in the domains assessed, whether negative or positive, would be expected to have a direct influence on the perception of change and global satisfaction with life.

On the other hand, we did not evaluate the divergent validity of the SHE, especially with separate measures of depression and anxiety, a fact that may be considered a limitation of the present study. This is because the literature indicates that about 30–50% of individuals with epilepsy have some type of psychiatric problem, anxiety and depression being the most frequent [26]. At the treatment center where the study was conducted, the estimated lifetime prevalence of depression among patients in the preoperative stage is 10%. The study of divergent validity would be important to assess the influence of these possible comorbidities on the perception of QOL.

Different results were observed in the groups regarding reliability. For the Pre group, whose retest interval was two days, the Kappa values were little expressive, in contrast with the findings of the original study. We wish to point out that the score of this group was higher in the retest than in the test despite the short interval between them. Some possibilities can be considered to explain this result. The first refers to the occurrence of postictal symptoms as part of the protocol of investigation performed during the period of hospitalization. Ictal events are known to be followed by a period of mental confusion and also of altered mood and physical status, a fact that may elicit interpretation or response biases. Although great care was taken to evaluate only patients who had not experienced seizures immediately before the interview and whose sensory system was fully functional, this hypothesis cannot be ruled out. Other variables that may have influenced the results are the type and frequency of seizures suffered by the participants, the drugs used at the time of the application of the instrument, and the side effects experienced and described by the patients. Analysis of these variables can confirm or rule out the hypotheses raised.

The evaluation of reliability in the outpatient groups showed better indices of agreement compared to hospitalized patients, supporting the hypothesis raised above that the SHE may not be adequate for hospitalized patients. However, the findings regarding the outpatient groups attest to the reliability of the SHE in this context.

In general, the SHE proved to be adequate for use in the Brazilian population of patients with epilepsy. For patients in acute situations and under diagnostic investigation, the instrument showed good validity but limited reliability, indicating limits of the instrument and of the patient himself inherent to his clinical condition. The instrument appears to be more appropriate in psychometric terms for the two outpatient groups with seizures controlled by surgery or by drugs.

Considering the specificity of the instrument for patients with epilepsy, the possible cognitive changes associated with the disorder, as well as the low educational level of the sample studied, we believe that a simpler scoring system based on a three-point Likert scale may be more appropriate, increasing the psychometric quality of the SHE.

The results reported here agree with those of the original study by O'Donoghue et al. [9], indicating that the objectives of the present study were achieved.

Appendix A. Supplementary data

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.yebeh.2012.04.129.

References

[1] Sander JM. The epidemiology of epilepsy revisited. Curr Opin Neurol 2003;16:165–70.
[2] Castel S. Distúrbios psíquicos não psicóticos interictais em epilepsia. Rev ABP-APAL 1993;15:39–43.
[3] Guldvog B. Patient satisfaction and epilepsy surgery. Epilepsia 1994;35:579–84.
[4] Vickrey BG, Hays RD, Engel Jr J, et al. Outcome assessment for epilepsy surgery: the impact of measuring health-related quality of life. Ann Neurol 1995;37:158–66.
[5] Vickrey BG, Hays RD, Rausch R, et al. Outcomes in 248 patients who had diagnostic evaluations for epilepsy surgery. Lancet 1995;346:1445–9.
[6] Kellett MW, Smith DF, Baker GA, Chadwick DW. Quality of life after epilepsy surgery. J Neurol Neurosurg Psychiatry 1997;63:52–8.
[7] Alonso NB, Ciconelli RM, Silva TI, et al. The Portuguese version of Epilepsy Surgery Inventory (ESI-55): cross-cultural adaptation and evaluation of psychometric properties. Epilepsy Behav 2006;9:126–32.
[8] da Silva TI, Ciconelli RM, Alonso NB, et al. Validity and reliability of the Portuguese version of the quality of life in epilepsy inventory (QOLIE-31) for Brazil. Epilepsy Behav 2007;10:234–41.
[9] O'Donoghue MF, Duncan JS, Sander JWAS. The subjective handicap of epilepsy. A new approach to measuring treatment outcome. Brain 1998;121:317–43.
[10] Guillemin F. Cross-cultural adaptation and validation of health status measures. Scand J Rheumatol 1995;24:61–3.
[11] Scientific Advisory Committee of the Medical Outcomes Trust. Assessing health status and quality of life instruments: attributes and review criteria. Qual Life Res 2002;11:193–205.
[12] Vickrey BG, Hays RD, Graber J, Rausch R, Engel Jr J, Brook RHA. Health-related quality of life instrument for patients evaluated for epilepsy surgery. Med Care 1992;30:299–319.
[13] Cronbach LJ. Coefficient alpha and the internal structure of tests. Psychometrika 1951;16:297–334.
[14] Zou KH, Tuncall K, Silverman S. Correlation and simple linear regression. Radiology 2003;227:617–28.
[15] Mclean RA, Sanders WL, Stroup WWA. Unified approach to mixed linear models. Am Stat 1991;45:54–64.
[16] Landis RJ, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1997;33:159–74.
[17] Markand ON, Salanova V, Whelihan E, Emsley CL. Health-related quality of life outcome in medically refractory epilepsy treated with anterior temporal lobectomy. Epilepsia 2000;41:749–59.
[18] Salgado PC, Souza EA. Quality of life in epilepsy and perception of seizures control. Arq Neuropsiquiatr 2001;59(3-A):537–40.
[19] Salgado PC, Souza EA. Impact of epilepsy at work: evaluation of quality of life. Arq Neuropsiquiatr 2002;60(2-B):442–5.
[20] Mohammed HS, Kaufman CB, Limbrick DD, et al. Impact of epilepsy surgery on seizure control and quality of life: a 26-year follow-up study. Epilepsia 2012;53(4):712–20.
[21] McLachlan RS, Rose KJ, Derry PA, Bonnar C, Blume WT, Girvin JP. Health-related quality of life and seizure control in temporal lobe epilepsy. Ann Neurol 1997;41(4):482–9.
[22] Seidman-Ripley JG, Bound VK, Andermann F, Olivier A, Gloor P, Feindel WH. Psychosocial consequences of postoperative seizure relief. Epilepsia 1993;34:248–54.
[23] Wilson SJ, Saling MM, Kincade P, Bladin PF. Patient expectations of temporal lobe surgery. Epilepsia 1998;39:167–74.
[24] Reid K, Herbert A, Baker GA. Epilepsy surgery: patient-perceived long-term costs and benefits. Epilepsy Behav 2004;5:81–7.
[25] Cankurtaran ES, Ulug B, Saygi S, Tiryaki A, Akalan N. Psychiatric morbidity, quality of life, and disability in mesial temporal lobe epilepsy patients before and after anterior temporal lobectomy. Epilepsy Behav 2005;7:116–22.
[26] Guarnieri R, Hallak JEC. Avaliação psiquiátrica em cirurgia de epilepsia. In: Sakamoto AC, Terra-Bustamante VC, Assirati Júnior JA, Carlotti Júnior, CG (Orgs.). Atualizações no tratamento cirúrgico das epilepsias 1st ed.; 2002;119–36.