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Development and Cross-Cultural Translations of a 31-Item Quality of Life in Epilepsy Inventory

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Summary: *Purpose:* We report the development of a questionnaire to assess health-related quality-of-life (HRQOL) in people with epilepsy and the process of cross-cultural translations of the questionnaire.

Methods: A sample of 304 adults with epilepsy from 25 seizure clinics in the United States was used to derive an abbreviated questionnaire focusing on epilepsy-related issues from a longer, 89-item instrument (QOLIE-89). A rigorous forward-backward-forward system was used for cross-cultural translation.

Results: A 31-item questionnaire (QOLIE-31, version 1.0) resulted, comprising seven subscales covering general and epilepsy-specific domains. Subscale and total scores can be calculated. The subscales were grouped into two factors: Emotional/Psychological Effects (seizure worry, overall QOL, emotional well-being, energy/fatigue subscales) and Medical/Social Effects (medication effects, work-driving-social limits, cognitive function subscales). Cross-cultural translations were made from U.S.-English into Danish, Dutch, German, Canadian French, French, Italian, Spanish, Swedish, and U.K. English Versions 1.1.

Conclusions: Our results support the reliability and validity of the QOLIE-31 (U.S.-English version 1.0) as a measure of HRQOLIE. Cross-cultural translations into nine other languages make it feasible to use the QOLIE-31 (version 1.1) in multinational clinical trials after validation in each population or concurrent with the clinical trial. **Key Words:** Health-related quality-of-life—Dimensions of health—Construct validity—Quality-of-Life in Epilepsy Inventory—Epilepsy—Translocations.

The individual patient's perspective has become an integral aspect of health care assessment (1). In epilepsy, clinicians are careful to obtain a social history along with physical and neurological examinations and medical history. The chronic nature of epilepsy, like that of most neurological disorders, often results in long-term relationships among the neurologist, the patient, and the patient's family. However, with recent changes in medical care delivery, less time is available to learn about the impact of the disorder on the patient's life. At the same time, the concept of quality of life (QOL) assessment has led to development of generic and disease-specific questionnaires to evaluate areas of concern to patients (2).

The purpose of addressing QOL include improving the quality of patient care, differentiating among treatment options, and evaluating the allocation of health care resources. The major domains of QOL are physical, psychological, and social issues (3). These areas go well beyond the traditional assessment of seizure frequency and severity, and adverse effects of medications, toward an understanding of the impact of epilepsy on daily life (1).

A variety of approaches have been used to assess QOL issues for people with epilepsy (2). Unified questionnaires [e.g., QOLIE-89 (4), ESI-55 (5)] and batteries of tests [e.g., Liverpool QOL Battery (6)] have been used for detailed research programs. However, to conduct multinational epilepsy studies that include assessments of QOL requires an instrument that has been rigorously translated and adapted to the culture of each country in which it will be used. Such instruments will allow researchers to compile and aggregate QOL data across sample populations from different countries. The process is complicated not only by the wide differences in the concept of what constitutes "health" among cultures,

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but also by the difficulty in achieving conceptual equivalence and consistency with the original instrument (7).

We report the initial development of a 31-item questionnaire—the QOLIE-31, version 1.0, abbreviated from the QOLIE-89 (4)—that focuses on specific areas of concern for people with epilepsy, and the process of linguistically and culturally developed translations (version 1.1). The QOLIE-31 was designed to serve as a brief assessment of epilepsy-specific and some overall QOL issues.

METHODS

Instrument development

A test questionnaire of 99 questions was used to develop the QOLIE-89, containing 89 items in 17 scales (4), including the seven scales of the RAND 36-Item Health Survey 1.0 (8,9) as the generic core. The QOLIE-31 was then derived from the QOLIE-89 as follows. In lieu of the statistical approach in which items with the highest loadings are selected for an abbreviated scale, we empirically selected QOLIE-89 subscales that were considered most important based on reports by people with epilepsy. Therefore, generic topics (e.g., pain) were excluded. These scales represent the issues commonly expressed by patients, as determined by an expert panel (QOLIE Development Group). The result was seven scales and an overall item, totaling 31 questions.

Instrument evaluation

The QOLIE 99-item test instrument was administered at the initial visit and was repeated 2–3 weeks later. In the absence of a true gold standard, we selected several widely used measures of external validity in addition to demographic characteristics (age, education, employment). The VA Systemic and Neuro Toxicity Scales (10) assessed signs that were objectively evaluated by a clinician (e.g., tremor, gait disorder) and symptoms that were reported by patients (e.g., gastrointestinal distress, tiredness) at the initial visit. These scales were used for 12 years in the VA Epilepsy studies for repeated assessments of 1,100 patients. A neuropsychological test battery, including measures of attention, memory/language, cognitive speed, motor speed, and mood, was completed by the patients during the first visit (11). The Profile of Mood States (POMS) (12) was used to assess tension, depression, anger, vigor, fatigue, and confusion. POMS has been widely used in epilepsy studies (e.g., VA Epilepsy Studies) as well as in many clinical neuropsychological test batteries.

Subject demographics

As detailed by Devinsky et al. (4), data were collected from 304 adult (mean age 36 years, range 17–60 years) epilepsy patients (43% male) for whom English was the primary language. Patients were recruited from 25 epilepsy clinics in the United States. Eligibility criteria included people who were functioning at a relatively normal level who could read and comprehend the questions. The QOLIE instruments were not intended for use by intellectually impaired patients. Mean age of epilepsy onset was 17.9 ± 12.1 years. Ninety-three percent of patients had a high school equivalency diploma or higher education. Other than having epilepsy and receiving antiepileptic drug (AED) treatment, patients had no significant medical or psychiatric illness, used no additional medication that could affect the CNS, and had not undergone a craniotomy in the past year. Patients with various types of seizures were categorized as having no seizures in the past year (none, n = 21) (but had at least one episode in the previous 12–24 months), or low (n = 116), moderate (n = 136), and high (n = 31) seizure frequency, based on the number of seizures in the past year (Table 1). Patients with more than one type of seizure were categorized based on the most severe seizure type.

Translations

Translation and cultural adaptation of the QOLIE-31 (version 1.0) was performed by MAPI Research Institute (Lyon, France) to translate questionnaires into the following target languages: Danish, Dutch, German, Canadian French, French, Italian, Spanish, Swedish, and U.K.-English (13). The translations are labeled version 1.1 in each language. The method included two independent forward translations into each of the target languages by 2 professional translators (native in the target language and bilingual in the source language of U.S.-English). A reconciled version was developed during a meeting between the forward translators and the country-specific QOL researcher. Thereafter, the reconciled translation was backtranslated into the source language (U.S.-English) by another professional translator. A second reconciliation meeting of the translation led to testing the instrument by "cognitive debriefing" (discussion of terminology) with 5 patients with epilepsy in each target country to assess clarity, appropriateness of wording, understandability, and cultural relevance of the

TABLE 1. *Seizure frequency and severity groups*

Seizure type	Frequency in past year			
	None[a] (n = 21)	Low (n = 116)	Moderate (n = 136)	High (n = 31)
Generalized tonic-clonic	0	1	2–4	5–12
Complex partial	0	1–4	5–12	13–24
Simple partial	0	1–20	21–100	101–200
Absence or myoclonic	0	1–20	21–100	101–200

[a] All patients had seizures in the 12–24 months before evaluation.

translated version. A meeting between the professional translators and QOL researchers was the final step to ensure that the original questionnaire and the translations measured the same concepts (international harmonization).

The original plan included agreement that the form of language adopted for each translation would suit the cultural preferences for each country (e.g., the Scandinavian version uses the familiar instead of the formal form. The French versions used both masculine and feminine forms, whereas the Italian and Spanish versions used the masculine form). All translations used the present perfect and perfect tense depending on the time reference.

Analyses

We assessed reliability of the QOLIE 99-item test instrument for test–retest data using Pearson correlation coefficients. Construct validity was assessed by the relationship between scales and other external measures (e.g., demographic characteristics, seizure frequency group, toxicity scores, neuropsychological test scores) hypothesized a priori to be related to the scale. Discriminant validity (to demonstrate that the operational definitions of the test constructs correlate positively with like measures of the same construct and negatively or neutrally with measures of dissimilar constructs) was assessed by univariate F-tests of scales and items with seizure groups. Chronbach α coefficients were calculated for each scale. Varimax rotation was used for factor analysis of the seven scales. Variables with loadings ≥ 0.4 were included in subscales.

Factor analyses were performed on the 30 constituent items in the QOLIE-31, and on the seven subscales. We hypothesized that greater seizure frequency, Systemic and Neuro-Toxicity scores, number of AEDs, number of medical visits, and worse mood (POMS) would be correlated with lower specific QOLIE-31 scale scores and the overall QOL subscale. Higher occupational status and level of education were expected to correlate with better QOLIE-31 scores. POMS scores were expected to correlate with emotional well-being and energy subscales.

Scoring

Details of the scoring system are provided in the QOLIE-31 Scoring Manual (14). Numeric values for responses to QOLIE-31 scales are devised so that higher and lower scores reflect better HRQOL and worse HRQOL and use ranges of values from 1 to 100. To account for these differences, the scoring system requires conversion from raw, precoded numeric values to scores of 0–100 points, with higher converted scores always reflecting better HRQOL. Converted scores for items can be summed and divided by the number of items in each scale that were answered to determine the Scale Score (range 0–100 points). Transformation to T-scores is described in the Scoring Manual. The total score is not a simple sum or mean of the seven subscales. An overall score can be calculated by weighting and summing the product of QOLIE-31 scale scores times its weight and summing over all scales using an empirically derived coefficient to weight and sum socres [Scoring Manual (14) is available on request].

RESULTS

Descriptive statistics and reliability (14)

Descriptive statistics are summarized in Table 2. All of the scales showed an adequate range of variability, with five scales showing the lowest absolute minimum of 0, and all seven scales showing the absolute maximum of 100. Mean scores ranged from 55 to 67, with SD ranging from 16 to 31. Internal consistency reliability coefficients (Chronbach α) ranged from $\alpha = 0.77$ (social functioning scale) to $\alpha = 0.85$ (cognitive functioning scale). Test–retest data demonstrated good reliability (range $r = 0.64$–0.85).

Multitrait scaling

Item to scale correlations (14) were calculated for the 30 items comprising the seven scales. In every instance, individual items correlated more significantly with the scale on which that item loaded than with other scales. Item–scale correlations were uniformly very high for all scales, including seizure worry ($r = 0.68$–0.79), overall QOL ($r = 0.90$–0.92), emotional well-being ($r = 0.71$–0.82), energy/fatigue ($r = 0.81$–0.85), cognitive functioning ($r = 0.66$–0.81), medication effects ($r = 0.75$–

TABLE 2. *Reliability, central tendency, and variability of QOLIE-31 scales*[a]

Scale	Reliability					
	No. of items	Alpha	Test-retest[b]	Mean (0–100 range)	SD	Observed range
Seizure worry	5	0.79	0.84	58	26	0–100
Overall QOL	2	0.79	0.84	67	18	5–100
Emotional well-being	5	0.83	0.77	67	19	16–100
Energy-fatigue	4	0.84	0.75	55	21	0–100
Cognitive functioning	6	0.85	0.85	60	23	0–100
Medication effects	3	0.78	0.64	55	31	0–100
Social functioning	5	0.77	0.82	67	27	0–100
Overall score	30	0.93[c]	0.89	63	16	15–97

QOLIE, quality of life in epilepsy

[a] Adapted from the QOLIE-31 Scoring Manual (14). The number of patients whose data were included in analyses ranged from 298 to 304 patients for all data except test-retest reliability.

[b] The number of patients whose data were included in test–retest analyses ranged from 229 to 232 in the subset of patients with epilepsy who were clinically stable and whose test–retest interval ranged from 1 to 21 days.

[c] Estimated using Mosier's formula (19).

0.89), and work/driving/social functioning (r = 0.69–0.80).

Factor analysis

Factor analysis of the 30 items yielded seven factors with eigenvalues >1.0. The items loading on 4 (numbers 2–5) of these factors were identical to the items in the constituent scales (seizure worry, cognitive functioning, medication effects, and social functioning). The first factor was more heterogeneous, containing high loadings from the 2 items constituting the overall QOL scale, 4 of the 5 items constituting the emotional well-being scale, and 1 of the 4 items constituting the energy/fatigue scale. This factor appears to represent mood and overall QOL. The sixth factor consisted of the remaining 3 items from the energy/fatigue scale, and the seventh factor consisted of the 1 remaining item from the emotional well-being scale. The factor analysis produced a structure that parallels the QOLIE-31 scale structure, with the exception of one heterogeneous factor representing broader QOL issues.

A separate factor analysis of the seven QOLIE-31 scales yielded two factors. The first factor, appearing to reflect emotional and psychological issues, comprised high loadings from the seizure worry, overall QOL, emotional well-being, and energy/fatigue scales. The second factor, appearing to reflect mental efficiency as medical/social effects, comprised high loadings from the medication effects, work/driving/social, and cognitive functioning scales.

Scale relationships to toxicity and seizure severity measures

Correlations were calculated between each score and the neurotoxicity and systemic toxicity scores. None of the correlations for systemic toxicity scores were significant (range r = 0.00–0.06). However, all correlations with neurotoxicity scores were statistically significant. Six of the scales were significantly correlated with neurotoxicity at $p < 0.0001$ (r = 0.24–0.36), and one scale (seizure worry) was significant at $p < 0.03$ (r = 0.12). Analyses of occupational status as a categorical variable [1, employed; 2, out of the workforce (retired, student, homemaker); 3, unemployed] showed significant differences for the overall scale [$p = 0.0001$; unemployed < employed), cognitive scale ($p = 0.003$; unemployed < employed and out of workforce], and the work scale ($p < 0.0010$; unemployed < employed and out of workforce). The number of AEDs was significantly associated with the work scale ($r = -0.171$, $p = 0.004$). Health care utilization, measured as the number of medical visits in the past year, was significantly associated with the total score ($r = -0.146$, $p = 0.016$) and subscales (work, $r = -0.182$ and $p = 0.002$; medical, $r = -0.136$ and $p = 0.020$).

POMS correlations with subscales are shown in Table 3. Although all seven subscales correlated well with each of the six POMS subscales (tension, depression, anger, vigor, fatigue, and confusion), energy and overall well-being had the strongest relationships.

A one-way analysis of variance (ANOVA) of seizure severity groups was significant ($F = 5.74$, $p = 0.0008$) for two of the scales. For the seizure worry scale, patients with high seizure frequency scored significantly worse (mean = 53.2) than patients whose seizures were controlled (mean 75.4, $p < 0.001$) and those with mild seizure frequency (mean 61.5, $p < 0.05$). For the social functioning scale, results of the overall ANOVA test were significant ($F = 7.21$, $p < 0.0001$) across the seizure severity groups, with the high seizure frequency group scoring worse (mean 56.9) than the controlled seizure group (mean 76.1, $p < 0.05$), and low seizure frequency group (mean 74.5, $p < 0.005$). Patients in the moderate seizure frequency group also scored worse (mean 62.1) than the low seizure frequency group ($p < 0.0009$).

Translations

International harmonization of the original QOLIE-31 (U.S.-English version 1.0) required a number of adaptations when there was no direct equivalent of the term, to avoid ambiguity, and to comply with local preferences. In the instructions, the word inventory, survey, or form was altered to "questionnaire" for readability; patients are asked to "ring" instead of "circle" their response

TABLE 3. *Correlations[a] between POMS subscales and QOLIE-31 subscales*

	QOLIE-31 subscales						
POMS	Social scale	Medical scale	Cognitive scale	Energy scale	Emotional scale	Overall QOL scale	Seizure worry scale
Tension	−0.26	−0.26	−0.41	−0.38	−0.64	−0.40	−0.37
Anger	−0.36	−0.28	−0.39	−0.46	−0.76	−0.60	−0.37
Depression	−0.26	−0.26	−0.26	−0.33	−0.60	−0.47	−0.34
Vigor (positive)	0.29	0.18	0.36	0.66	0.52	0.56	0.17
Fatigue	−0.25	−0.31	−0.40	−0.70	−0.54	−0.43	−0.29
Confusion	−0.39	−0.29	−0.69	−0.45	−0.53	−0.45	−0.34

POMS, Profiles of Mood States; QOLIE, quality of life in epilepsy.
[a] Pearson correlation matrix.

[or mark with a cross (X) in Germany]; to avoid ambiguity, patients are instructed specifically to write comments in the "left margin."

Item 1, "How you would rate your QOL" was not problematic, except that the German translation required a longer sentence to convey the question. Items 2–10 used the translations previously established for the Medical Outcome Study Short Form-36 (MOS SF-36) (7,15) questionnaire, with adjustment made for tense in the German version. Items 11-20 required several changes in terms (e.g., in term 11, "worry" was replaced by "fear" in French and Dutch; in item 13, "social activities" was replaced by "relationship with others"). Item 14 responses were changed to past tense for consistency. Items 15 and 16, which refer to memory, were difficult to translate, requiring an instruction for item 15 to "circle one number" above the responses, which allowed item 16 to be simplified to: "How often during the past 4 weeks have you had trouble remembering or how has this memory problem interfered with your normal work or living?" (circle one number). However, to convey the appropriate concept, "living" (item 16) had to be adapted to "daily life" in Dutch, Italian, Spanish, and Swedish; "everyday life" in both French versions, and just "life" in Danish and German. Item 20, which refers to difficulties with driving and mobility was the most difficult to translate. Interpretation of the word "driving" (ranging from driving a car, riding a bicycle, riding a bus, to driving a motorbike), led to adoption of alternative wording such as driving a car, or driving a motorbike.

Item 21 was redefined as encompassing the "next 4 weeks" instead of "next month." In item 24, the phrase "medications you are taking" was altered in German because the original translated as "medications you are given." Item 29 referring to "effects of epilepsy medication" required change to "side-effects" to convey the intended negative connotation in Dutch, because "effects" could be construed as positive. In item 30, the term "mental" was translatable only into Spanish. The concept was changed to "psychological or behavioral effects" to maintain the original concept in all other translations.

DISCUSSION

We report the reliability and validity of an abbreviated, 31-item questionnaire for assessing QOL in epilepsy: the QOLIE-31 (version 1.0 U.S.-English). The QOLIE-31 was designed to serve as an epilepsy-specific instrument for rapid evaluation of the major HRQOL domains of concern of adults with epilepsy. Although this instrument assesses fewer domains than the lengthy QOLIE-89 with 17 scales, the seven scales selected for the QOLIE-31 approach those areas directly applicable to people with epilepsy, omitting scales with a relatively generic QOL target (e.g., pain, role limitations-physical). The selection of subscales most relevant to people with epilepsy is further confirmed by other studies of patient preferences. The issues tabulated by Gilliam et al. (16) for a U.S. sample of 81 patients are included in QOLIE-31 questions (e.g., driving, independence, employment, social concerns, medication dependence, mood).

The QOLIE-31 is a more detailed instrument than the QOLIE-10 (17), a brief screening tool that contains one item for each area covered in the QOLIE-31. When patients are asked several questions about each issue, they are allowed to consider their concerns from several angles that are averaged in the scale score, which increases reliability. In addition, the overall score provides a summary of the scale scores. The QOLIE-31 should be useful in clinical practice for longitudinal observation or evaluation of response to a change in treatment (e.g., medication change or surgery), as well as in clinical trials (e.g., when a medication is added, substituted, or initiated). The QOLIE-31 is already more widely used internationally than the longer QOLIE-89, largely because of the brevity of the questionnaire and the simplicity of scoring. The small patient burden in responding to 31 questions should allow convenient and repeated use over time. A drawback to the use of all the QOLIE instruments is their limitation to use in adults who can read and comprehend the questions, usually requiring reading ability at the 10- to 12-year-old level. Other questionnaires are being developed for use in adolescents (18) and children.

The scale and total scores correlated inversely with the seizure frequency groups, tending to show better QOL for patients with no seizures in the past year and declining QOL scores as seizure frequency increased. Therefore, the total QOLIE-31 score provides information similar to the total QOLIE-89 score. These data suggest that the selection of seven subscales for the QOLIE-31 may be a reasonable substitute for the lengthier QOLIE-89 to provide a general picture of the QOL of people with epilepsy.

The correlations of QOLIE-31 subscales with Neurotoxicity scores is assumed to be related to the predominantly CNS effects of seizures and medications. The low correlations for Systemic Toxicity may reflect the weighting of that scale with many clinically objective items that are not reflected in patient reports. The association of POMS subscales with QOLIE-31 subscales (Table 3) likely reflects the pervasive state of anxiety and depression among people with epilepsy. Perrine et al. (11) described the correlation of QOLIE-89 subscales with a lengthy neuropsychological test battery, suggesting that additional studies are required to ascertain whether mood drives QOL or vice versa.

The rigorous translation and cross-cultural adaptation of the QOLIE-31 has resulted in a series of question-

naires (versions 1.1) that remain consistent with the original U.S.-English version 1.0. Nonetheless, a number of problems were encountered during the process. In most languages, longer and more structurally demanding questions were more confusing than shorter, more concise questions. Some confusion was related to inconsistency among response options and changes in the number of responses. Many words and phrases could not be translated literally and required clarification for interpretation. Some phrases in vernacular U.S.-English that were not understandable required adaptation for other cultures. These problems were resolved with expert panels, multiple translations, and reviews of cultural and linguistic differences, leading to establishment of consistent meanings among the different languages. The availability of the QOLIE-31 in nine languages will allow its use in multinational clinical trials and other studies of HRQOL. The feasibility of comparing data among international populations with epilepsy should provide useful information about the impact of seizure disorders in various countries.

The usefulness of the QOLIE-31 as compared with the more detailed QOLIE-89, the less detailed QOLIE-10 (17), or other instruments, will be identified in other prospecitve studies. When ongoing validation studies are reported, the availability of rigorous linguistic and cross-culturally adapted translations of the QOLIE-31 (version 1.0) will help ensure that differences among patients in various countries in item and scale scores are due to real differences in health status and not to inadequate or misleading translations of the questionnaire. Subscale weighting should also be revised for different populations. The version 1.1 questionnaires are undergoing validity and reliability testing in each country to allow full evaluation of the translations as part of ongoing clinical trials in which these studies are most readily accomplished.

The QOLIE-31 may become the most useful of the three QOLIE instruments for adults (89-, 31-, 10-item versions). Reports of QOLIE-31 data from ongoing clinical trials and surgical follow-up samples will provide information about the degree of change that represents a clinically important difference in domains of HRQOL.

APPENDIX 1.

QOLIE-31 (Version 1.0, U.S.-English) Patient Inventory[1]

1. Overall, how would you rate your quality of life? Circle one number on a scale from 10 (Best Possible QOL) to 0 (Worst Possible QOL, as bad as or worse than being dead)

   These questions are about how you FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. . .(Circle one number on a scale ranging from 1 [All of the time] to 6 [None of the time].)
2. Did you feel full of pep?
3. Have you been a nervous person?
4. Have you felt so down in the dumps that nothing could cheer you up?
5. Have you felt calm and peaceful?
6. Did you have a lot of energy?
7. Have you felt downhearted and blue?
8. Did you feel worn out?
9. Have you been a happy person?
10. Did you feel tired?
11. Have you worried about having another seizure?
12. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?
13. Has your health limited your social activities (such as visiting with friends or close relatives)?
14. How has the quality of your life been during the past 4 weeks (that is, how have things been going for you)? (Dartmouth Coop Chart 1–5) (Circle one number on a ladder scale ranging from 1 = Very well: could hardly be better, to 5 = Very bad: could hardly be worse)
15. In the past 4 weeks, have you had any trouble with your memory? (Circle one number between 1 and 4.) 1 = yes, a great deal; 4 = No, not at all)
16. Circle one number for how often in the past 4 weeks you have had trouble remembering or how often this memory problem has interfered with your normal work or living. Trouble remembering things people tell you. (Circle one number on a scale from 1 = All of the time to 6 = none of the time)

    The following questions are about CONCENTRATION problems you may have. Circle one number for how often in the past 4 weeks you had trouble concentrating or how often these problems interfered with your normal work or living. (Circle one number on a scale from 1 = All of the time to 6 = None of the time)
17. Trouble concentrating on reading
18. Trouble concentrating on doing one thing at a time

    The following questions are about problems you may have with certain ACTIVITIES. Circle

[1] Copyright held by RAND. Permission to use the QOLIE-31 (Version 1.0 U.S.-English) may be obtained from RAND, 1700 Main St., P.O. Box 2138, Santa Monica, CA 90407-2138, U.S.A. Attention: Contracts and Grants Services.

one number for how much during the past 4 weeks your epilepsy or antiepileptic medication has caused trouble with. . . (Circle one number on a scale from 1 = A great deal to 6 = Not at all)

19. Leisure time (such as hobbies, going out)
20. Driving

The following questions relate to the way you FEEL about your seizures.

21. How fearful are you of having a seizure during the next month? (Circle one number on a scale from 1 = Very fearful to 4 = Not fearful at all)
22. Do you worry about hurting yourself during a seizure? (Circle one number on a scale from 1 = Worry a lot to 3 = Don't worry at all)
23. How worried are you about embarrassment or other social problems resulting from having a seizure during the next month? (Circle one number on a scale from 1 = Very worried to 4 = Not worried at all)
24. How worried are you that medications you are taking will be bad for you if taken for a long time? (Circle one number on a scale from 1 = Very worried to 4 = Not worried at all)

For each of these PROBLEMS, circle one number for how much they bother you (on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome).

25. Seizures
26. Memory difficulties
27. Work limitations
28. Social limitations
29. Physical effects of antiepileptic medication
30. Mental effects of antiepileptic medication
31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. Please consider your epilepsy as part of your health when you answer this question. (Thermometer scale 100 = Best Imaginable Health State to 0 = Worst Imaginable Health State (as bad as or worse than being dead)

Scale/item numbers

Seizure Worry: 11, 21–25
Overall Quality of Life: 1, 14
Emotional well-being: 3–5, 7, 9
Energy/fatigue: 2, 6, 8, 10
Cognitive: 12, 15–18, 26
Medication effects: 24, 29, 30
Social function: 13, 19, 20, 27, 28

Single Item:

Overall health: 31 (not included in scoring)

Sources for items on QOLIE-31

1	Adapted from Faces Scale (20) by Hadorn and Hays (21).
2, 6, 8, 10	Energy/Fatigue Scale (from SF-36) (8,9)
3, 5, 5, 7, 9	Emotional Well-Being Scale (from SF-36) (8,9)
11, 15	From ESI-55 (5)
12, 13	MOS (22)
14	Dartmouth COOP Chart (23)
16–30	Developed de novo by QOLIE Development Group
31	Adapted from existing measure (15)

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