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FULL LENGTH ORIGINAL RESEARCH

Epilepsia®

# Development and validation of the Epilepsy Surgery Satisfaction Questionnaire (ESSQ-19)

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## Abstract

**Objective:** No validated tools exist to assess satisfaction with epilepsy surgery. We aimed to develop and validate a new measure of patient satisfaction with epilepsy surgery, the 19-item Epilepsy Surgery Satisfaction Questionnaire (ESSQ-19).

**Methods:** An initial 31-item measure was developed based on literature review, patient focus groups, thematic analysis, and Delphi panels. The questionnaire was administered twice, 4-6 weeks apart, to 229 adults (≥18 years old) who underwent epilepsy surgery ≥1 year earlier, at three centers in Canada and one in Sweden. Participants also completed seven validated questionnaires to assess construct validity. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) assessed the factorial structure of the questionnaire. Cronbach alpha and intraclass correlation coefficients (ICCs) assessed the internal consistency and test-retest reliability of the ESSQ-19. Spearman and polyserial correlations assessed construct validity.

**Results:** Median age of participants and time since surgery were 42 years (interquartile range [IQR] = 32-54) and 5 years (IQR = 2-8.75), respectively. EFA and CFA yielded 18 items that segregated into four domains (mean score [SD]), namely, seizure control (76.4 [25]), psychosocial functioning (67.3 [26]), surgical complications (84 [22]), and recovery from surgery (73 [24]), one global satisfaction item, and a summary global score (74 [21]). The domain and summary scores demonstrated good to excellent internal reliability (Cronbach α range = .84-.95) and test-retest reliability (ICC range = 0.71-0.85). Construct validity was supported by predicted correlations with other instruments.

**Significance:** The ESSQ-19 is a new, valid, and reliable measure of patient satisfaction with epilepsy surgery that can be used in clinical and research settings.

[Correction added on 21 October 2020, after first online publication: the title has been corrected to "Development and validation of the Epilepsy Surgery Satisfaction Questionnaire (ESSQ-19)"]

KEYWORDS
epilepsy surgery, patient satisfaction, patient-reported outcomes, questionnaire

## 1 | INTRODUCTION

Treatment satisfaction can be defined as an individual's rating of important attributes of the process and outcomes of the treatment experience,[1] and it is an important determinant of adherence to medication and perception of outcomes such as quality of life.[2,3] Treatment satisfaction measures differ from health status or quality of life measures in that the latter assess the outcomes of treatment (eg, biological, symptoms, functioning, and well-being), and treatment satisfaction scales assess the level of satisfaction with these health status outcomes.[4] As a construct, satisfaction with treatment differs also from satisfaction with the process of health care. The latter focuses on the value of health care services and is closely related to consumer satisfaction, emphasizing aspects such as communication, empathy, and continuity of care, as outlined in the widely used Medical Outcomes Study.[5] Satisfaction with medical treatment, on the other hand, captures the perception of effectiveness, side effects, and convenience of interventions.[6] Satisfaction with surgical interventions includes additional elements such as invasiveness, discomfort, recovery from surgery, and permanence of the procedure. A previous systematic review found only eight studies assessing satisfaction with epilepsy surgery in some manner.[7] These studies assessed satisfaction using a variety of nonvalidated questions, often with dichotomous answers, using constructs such as success or failure, positive or negative impact, or willingness to repeat surgery. Neither of these items adequately measures the construct of treatment satisfaction.[4]

We postulate that an instrument that measures satisfaction with various aspects of epilepsy surgery (eg, presurgical investigations and surgical intervention, recovery from surgery, complications, seizure outcome and expectations) will increase our understanding of important patient-reported outcomes. Identifying elements that influence satisfaction with surgery and their interaction with clinical, quality of life, and psychosocial outcomes will significantly enhance our ability to counsel individual patients preoperatively, weigh various aspects of the surgical experience, inform surgical decision-making, and obtain a more comprehensive, patient-centered picture of the effect of surgery. We also hypothesize that a valid measure of satisfaction with surgery will correlate more strongly with epilepsy-specific clinical outcomes, quality of life, and depression than generic instruments and those that are less relevant to epilepsy surgery. Moreover, such an instrument will also help us uncover associations with satisfaction with surgery that are not readily apparent.

**Key Points**

- There is a need for valid instruments to assess satisfaction with epilepsy surgery
- Using rigorous methodology, we derived and validated a 19-item self-administered questionnaire, the ESSQ-19
- ESSQ-19 comprises four domains (seizure control, psychosocial functioning, surgical complications, recovery from surgery) and one global satisfaction item
- The new, valid, and reliable ESSQ-19 can be used in clinical and research settings
- Further evaluation of the ESSQ-19 is required across different languages, and to measure clinical change over time

We have previously reported on a conceptual framework to assess patient-informed satisfaction with epilepsy surgery.[8] Using a systematic review of the literature, patient focus groups, and Delphi panel consensus of experts, we distilled a list of 31 items that adequately explored treatment satisfaction with epilepsy surgery. Here, we report on the derivation and validation of the 19-item Epilepsy Surgery Satisfaction Questionnaire (ESSQ-19).

## 2 | MATERIALS AND METHODS

### 2.1 | Conceptual framework and item generation

A detailed description of the conceptual framework and item generation methodology of the ESSQ-19 is provided elsewhere.[8] In summary, following a systematic review of epilepsy surgery satisfaction literature,[7] we conducted an iterative process involving two focus groups of consenting adults (n = 9) who had undergone different types of epilepsy surgery. This yielded an initial 55-item questionnaire, comprising 12 domains relevant to patient satisfaction with epilepsy surgery, namely, adverse effects, medical care or rehabilitation, seizure control, postoperative recovery, antiseizure medication, independence, seizure worry, ability to drive, social relationships, self-confidence, improved cognitive function, and improved physical health. The domains

and the list of items were then refined through two iterations of a Delphi expert panel (n = 13) composed of neurologists, neurosurgeons, and psychologists. Item relevance and clarity were assured using member-checking methods involving focus group participants. This yielded a 31-item questionnaire (ESSQ-31) that preserved the 12 domains and was submitted to exploratory and confirmatory factor analysis and item reduction. An item-tracking matrix was used to document changes to the original list of items.

## 2.2 | Questionnaire format and response options

The ESSQ-31 asked respondents about their level of satisfaction with surgery, based on how they feel currently or in the past 4 weeks. Items had between five and seven Likert-type response options, plus a nonapplicable option when needed. Five-point scales were used for unidimensional continua (eg, extremely dissatisfied to not at all dissatisfied), whereas 7-point scales were used for bipolar continua (eg, extremely satisfied to extremely dissatisfied). This provided roughly equivalent rating intervals across items. Because patients tend to rate their experience with epilepsy surgery as satisfactory,[7] nonneutral midpoints were used for 7-point scales, resulting in a greater range of positive than negative response options for these items. This approach aims at reducing scale resolution problems associated with the upper end of skewed distributions.[6] Wording of the questions and responses was largely based on the widely used and validated Treatment Satisfaction Questionnaire.[6] Readability was assessed with the Flesch-Kincaid readability test.[9]

## 2.3 | Study population

To participate in the validation study, patients had to fulfill all of the following criteria: age ≥ 18 years at time of recruitment; having had resective or disconnective epilepsy surgery ≥1 year earlier to allow for stable postsurgical state; capacity to provide consent; ability to answer questionnaires; and cognitive and physical capacity to complete self-administered questionnaires without the need for a proxy. Patients were excluded if surgery was only for intracranial electroencephalography (EEG) or if surgery was primarily done to treat an underlying lesion that produced seizures, rather than epilepsy surgery proper. Participants were recruited from epilepsy clinics at three centers in Canada (Calgary, Saskatoon and Montreal) and one in Sweden (Gothenburg) from September 2016 to October 2019. We aimed to recruit 270 participants, sufficient for an approximate subject to item ratio of 10, as recommended for exploratory factor analyses, acknowledging that a wide range of sample sizes has been suggested, with subject to item ratios as low as two, and total subjects ranging from 50 to hundreds, and a recent guidance suggesting a ratio of seven and a total sample of ≥50.[10,11]

## 2.4 | Validation procedure

The ESSQ-31 was translated from English to Canadian French and Swedish using a rigorous process of professional translation and back-translation and testing. All instruments administered used validated versions in English, Canadian French, and Swedish (see Appendix S1—Supporting Information).

All participants completed a battery of self-administered questionnaires at baseline and the ESSQ-31 twice, 4-6 weeks apart. The battery included (1) the ESSQ-31[8]; (2) the EuroQOL five-dimension five-level health utility scale (EQ-5D-5L),[12] where higher scores indicate greater health state valuation; (3) the Patient Health Questionnaire (PHQ-9),[13] -a depression rating scale, where higher scores indicate a greater severity of depression; (4) the Marlowe-Crowne Social Desirability Scale, Short Form C (MCSDS-C),[14] where higher scores indicate a greater degree of social desirability; (5) the Treatment Satisfaction Questionnaire for Medication (TSQM-II),[15] where higher scores indicate greater treatment satisfaction; (6) the Global Assessment of Severity of Epilepsy scale (GASE),[16] where lower scores indicate greater self-perceived epilepsy severity; (7) the Global Assessment of Disability for Seizure Disorders scale (GADS),[17] where lower scores indicate greater self-perceived epilepsy disability; and (8) the Patient-Weighted Quality of Life in Epilepsy (QOLIE-31-P)[18] scale, where higher scores indicate a greater self-perceived quality of life. In addition, demographic and clinical data were obtained for each participant, including age, education, marital status, employment status, year of epilepsy onset, seizure type and frequency, current antiepileptic drugs, date and type of surgery, and surgical complications.

## 2.5 | Factor analysis and item reduction

The Likert-type responses for each of the 30 items of the ESSQ-31 were converted into 0- to 100-point scores, where 0 indicates the worst possible level of satisfaction and 100 the best possible level of satisfaction (see Appendix S1 for scoring instructions).

Exploratory factor analysis (EFA) using varimax rotation with Kaiser normalization, and maximum likelihood extraction method was used to determine the number and type of factors from the 30 items of the ESSQ-31 (the item on global satisfaction with epilepsy surgery was not included).[8] EFA was performed on complete data for all 30 items at baseline. A factor solution from the EFA was obtained based on the magnitude of each item's factor loadings. Item elimination used standard

psychometric criteria, such that items with factor loading < 0.6 were eliminated. Clinical experts assessed whether exclusion and retention of specific items made clinical sense. Following item elimination, a factor score for each of the domains was derived using the factor loadings to weight each item's contribution to that domain. The factor scores were then averaged to produce a summary score of the ESSQ-19.

Based on the results of the EFA, the factor solution was tested using confirmatory factor analysis (CFA). The primary goal of CFA was to assess the model fit of the factorial structure using root mean square error of approximation (RMSEA; where <0.08 is considered acceptable and <0.06 is considered excellent) and comparative fit index (CFI; where >0.95 is considered acceptable). This yielded a 19-item final questionnaire, the ESSQ-19, consisting of 18 items tapping into various aspects of satisfaction with epilepsy surgery, which loaded into four factors (see below). One additional global item assessed global satisfaction. Clinical experts assessed whether the factor solution and factor loadings made clinical sense. Floor and ceiling effects were assessed for each item and each of the four domains.

### 2.6 | Reliability and validity

Internal consistency reliability of the ESSQ-19 was assessed using Cronbach alpha. The estimates of reliability should exceed .70 ($.7 \leq \alpha < .8$ is acceptable, $.8 \leq \alpha < .9$ is good, and $.9 \leq \alpha$ is excellent). Intraclass correlation coefficient (ICC) evaluated test-retest reliability of ESSQ-19 domain and summary scores between the first and second administration of the questionnaire. Construct validity was assessed using Spearman and polyserial correlations of the EFA-yielded domains and ESSQ-19 summary score with the seven validated questionnaires, namely, EQ-5D-5L (using the visual analogue scale [VAS]), PHQ-9, MCSDS-C, TSQM-II (using the Global Satisfaction domain), GASE, GADS, and QOLIE-31-P. We hypothesized a priori that the ESSQ-19 summary score would have a higher correlation with epilepsy-specific and quality of life questionnaires (eg, QOLIE-31-P, EQ-5D-5L), because satisfaction with treatment and quality of life are associated, and lower correlation with aspects that are less relevant to epilepsy surgery, such as the social desirability scale MCSDS-C, which does not directly explore epilepsy surgery and is more related to the need to be seen in a positive light by others.

Floor and ceiling effects were assessed as the proportion of patients scoring at the lowest or highest range, respectively. Only questionnaires with complete data were included; there was no imputation of missing data. All data were collected, managed, stored, and extracted using iDataFax, an electronic data capture tool hosted by the Clinical Research Unit at the University of Calgary. Data management was performed using SAS 9.4. All statistical analyses were conducted using SPSS V.25.0 and AMOS 25. Statistical significance was set at $P \leq .05$ (two-sided).

### 2.7 | Ethics

Ethics approval for the study was obtained through the University of Calgary's Conjoint Health Research Ethics Board (No. REB13-0882), and for every participating institution. Written informed consent was obtained from all participants.

## 3 | RESULTS

Within the planned study period, we recruited 229 patients whose clinical and demographic characteristics are described in Table 1. Of 229 participants, 132 (57.6%) were recruited from Calgary, 32 (14%) from Montreal, 38 (16.6%) from Saskatoon, and 27 (11.8%) from Sweden. Patients from different centers and speaking different languages were similar in age, gender, duration of epilepsy, type of epilepsy, use of intracranial EEG, seizure freedom since surgery, and scores of most instruments. Patients from Sweden tended to have fewer years of education, higher rates of employment, and lower scores on the PHQ-9.

### 3.1 | Exploratory and confirmatory factor analysis

Of the 229 recruited patients, 24 did not complete all questionnaires. A total of 205 participants (90%) had complete data on the ESSQ-31 and constitute the population used for factor analysis; this is considered of sufficient size for EFA by recent recommendations.[10,11] EFA of the 30 items (ie, excluding the item rating global satisfaction) produced a four-factor solution based on the magnitude of each item's factor loadings (Table 2). Items with factor loading > 0.6 were retained. The majority of items had a factor loading > 0.7. A total of 12 items were removed due to their low factor loading and lower clinical relevance as assessed by clinical experts. EFA yielded an 18-item solution loading into four factors representing four domains: seizure control (five items), psychosocial functioning (seven items), surgical complications (three items), and recovery from surgery (three items), in addition to one global satisfaction item not included in the EFA; this constitutes the ESSQ-19. Experienced epileptologists confirmed the clinical relevance and domain distribution of the final 18 items. Items 2 and 3 (seizure control domain) ask about the impact of epilepsy surgery on specific aspects of seizures (ie, seizure-related injuries and postictal effects). Although seizure-free patients could have been instructed not to complete these two items,

**TABLE 1** Demographic and clinical characteristics of participants

| Characteristic | Total cohort, N = 229 |
|---|---|
| Age, y, median (IQR) | 42 (32-54) |
| Female, n (%) | 127 (55.5) |
| Marital status, n (%) | |
| Single | 87 (38.0) |
| Married or common law | 107 (46.8) |
| Separated/divorced/widowed | 31 (13.6) |
| Education, n (%) | |
| <12 y | 37 (16.1) |
| 12-15 y | 144 (62.8) |
| ≥16 y | 44 (19.3) |
| Employed, n (%) | 127 (55.5) |
| Duration of epilepsy before surgery, y, median (IQR) | 18 (8-28) |
| Intracranial EEG, n (%) | 67 (29.3) |
| Temporal lobe surgery, n (%) | 180 (78.6) |
| Complications of surgery, n (%) | 68 (29.7) |
| Permanent | 30 (13.1)[a] |
| 1 year seizure-free at time of survey, n (%) | 135 (59.0) |
| Seizure type at time of survey, n (%) | |
| Focal aware and/or focal impaired awareness | 85 (37.1) |
| Generalized tonic-clonic | 23 (10.1) |
| Time since surgery, y, median (IQR) | 5 (2-8.75) |
| AED use at time of survey, n (%) | |
| No AEDs | 22 (9.6) |
| Monotherapy | 67 (29.3) |
| Polytherapy | 139 (60.7) |
| QOLIE-31-P, mean (SD) | 70.6 (16.5) |
| EQ-5D-5L VAS, mean (SD) | 76.7 (18.2) |
| PHQ-9 score ≥ 10, n (%) | 53 (23.1) |
| MCSDS-C, median (IQR) | 9 (7-11) |
| GASE, median (IQR) | 7 (6-7) |
| GADS, median (IQR) | 6 (5-7) |
| TSQM-II Global Satisfaction, mean (SD) | 71.3 (24.3) |

*Note:* Numbers and percentages may not add up to the appropriate totals as a result of missing data or not mutually exclusive categories.

Abbreviations: AED, antiepileptic drug; EEG, electroencephalography; EQ-5D-5L VAS, EuroQOL five-dimension five-level visual analogue scale; GADS, Global Assessment of Disability for Seizure Disorders; GASE, Global Assessment of Severity of Epilepsy; IQR, interquartile range; MCSDS-C, Marlowe-Crowne Social Desirability Scale, Short Form C; PHQ-9, Patient Health Questionnaire; QOLIE-31-P, Patient-Weighted Quality of Life in Epilepsy; TSQM-II, Treatment Satisfaction Questionnaire for Medication–Version 2.

[a]Of the 30 participants who had permanent complications of surgery, 24 had one, and six had two permanent complications. Seven had a visual field deficit, four had dysphasia, four had hemiparesis, three had psychiatric issues, and 18 had cognitive or memory issues.

seizure-free patients valued being able to rate their satisfaction in these domains after being rendered seizure-free, and the items were retained for all patients. The ESSQ-19 instrument in English, Canadian French, and Swedish, and scoring instructions are presented in Appendix S1. This 19-item questionnaire explained 73.33% of the total variance. CFA of the factor structure of the ESSQ-19 (Figure 1) demonstrated acceptable fit: RMSEA = 0.064 (90% confidence interval = 0.052-0.077) and CFI = 0.969.

## 3.2 | Psychometric properties

Internal consistency reliability (Cronbach alpha) of the four domains of the ESSQ-19 ranged from .84 to .95 (Table 3), corresponding to good to excellent internal reliability. Test-retest reliability (ICC) for ESSQ-19 domains and summary score was good to excellent, ranging from 0.71 to 0.85, and it was 0.85 for the summary score.

## 3.3 | Construct validity

The correlation of the four ESSQ-19 domain scores ranged from moderate to high for QOLIE-31-P total score (0.55-0.72, $P < .01$), EQ-5D-5L VAS (0.41-0.66, $P < .01$), GADS scores (0.42-0.57, $P < .01$), and PHQ-9 (−0.37 to −0.61, $P < .01$). Correlations were lower for MCSDS-C (0.30-0.44, $P < .01$), GASE (0.28-0.56, $P < .01$), and TSQM-II global satisfaction (0.27-0.49; Figure 2; Table S1, Supporting Information). As hypothesized, the ESSQ-19 summary score correlated most strongly with epilepsy-specific and quality of life instruments QOLIE-31-P (0.77) and EQ-5D-5L (0.65), and least with the MCSDS-C (0.47) and TSQM-II (0.50), which are less relevant to epilepsy surgery satisfaction. The correlation was intermediate for disability (GADS = 0.62) and severity (GASE = 0.52) of epilepsy (Figure 2; Table S1).

## 3.4 | Instrument score, and floor and ceiling effects

The ESSQ-19 scores range from 0 to 100, where higher scores represent higher levels of satisfaction. The mean scores of each of the four domains ranged from 67.3 (psychosocial functioning) to 84.0 (surgical complications), and the global summary score was 73.5 (Table 3). None of the four domains of the ESSQ-19 demonstrated a significant floor effect, and only the domain of surgical complications exhibited a substantial ceiling effect (48%), explained by the finding that most patients (70%) did not have surgical complications. The floor and ceiling effects of the summary score were 0.49% and 3.41%, respectively (Table S2, Supporting Information).

**TABLE 2** Individual items of the 19-item Epilepsy Surgery Satisfaction Questionnaire and their factor solution

| Factors | Factor loading |
|---|---|
| Factor 1: seizure control domain (5 items) | |
| 1) Seizure control | 0.814 |
| 2) Prevent accidents or injuries caused by seizures | 0.768 |
| 3) How you feel after a seizure | 0.708 |
| 4) How much you worry about having a seizure | 0.684 |
| 5) Met your expectations | 0.648 |
| Factor 2: psychosocial functioning domain (7 items) | |
| 6) Social life | 0.754 |
| 7) Performance at work (including domestic), school, or volunteering | 0.761 |
| 8) Self-confidence | 0.776 |
| 9) Cognitive function, such as memory, ability to think and speak clearly, etc | 0.724 |
| 10) Mood | 0.742 |
| 11) Overall physical health | 0.671 |
| 12) Overall quality of life | 0.765 |
| Factor 3: surgical complications domain (3 items) | |
| 13) Poor balance or coordination | 0.738 |
| 14) Muscle weakness | 0.922 |
| 15) Decreased sensation (eg, numbness) | 0.632 |
| Factor 4: recovery from surgery domain (3 items) | |
| 16) Speed of recovery in hospital | 0.816 |
| 17) Recovery after discharge from the hospital (not including rehabilitation) | 0.812 |
| 18) Rehabilitation after discharge from the hospital | 0.730 |
| Global satisfaction item | |
| 19) Taking into account all aspects of your epilepsy surgery, how satisfied or dissatisfied are you with your epilepsy surgery? | |

### 3.5 | Usability and respondent burden

The self-administered ESSQ-19 matched grade 8-10 readability levels for the different items and took approximately 8 minutes to complete. Participants did not find the questionnaire onerous or difficult to complete, as demonstrated by a very high level of questionnaire return and completeness.

## 4 | DISCUSSION

The concept of satisfaction with epilepsy treatment in general and epilepsy surgery in particular has received little attention. Measuring treatment satisfaction is important because it reflects how patients interpret various health states, including quality of life, in relation to interventions, and it sheds light onto aspects of the intervention that are important to patients. Thus, treatment satisfaction adds another dimension to the assessment of patient-reported outcomes, and although validated generic tools to assess satisfaction with medication are available and have been used in epilepsy,[19] no such instruments exist to assess satisfaction with epilepsy surgery.[7]

Using rigorous methodology, we derived and validated a 19-item, self-administered questionnaire (ESSQ-19) to assess satisfaction with epilepsy surgery, comprising four domains, namely, seizure control, psychosocial functioning, surgical complications, and recovery from surgery, and one global question of satisfaction. Psychometric properties such as internal consistency and test-retest reliability were good to excellent. The ESSQ-19 exhibited adequate construct validity as evidenced by correlation with other instruments ranging from 0.47 to 0.77 in the summary score. As hypothesized, among all instruments used for construct validity, the MCSDS-C (social desirability) had the lowest correlation with each of the four domains of the ESSQ-19, except for "recovery from surgery"; and correlations were stronger for epilepsy-specific and quality of life instruments (Figure 2; Table S1). The magnitude of these correlations is also in keeping with those reported between treatment satisfaction and quality of life in other conditions.[4] The lower correlation of the GASE (epilepsy severity) scale with the ESSQ-19 domains of Surgical Complications (0.32) and Recovery from Surgery (0.28) is expected and reflects that these specific aspects of the surgical intervention are minimally related to the severity of epilepsy. This provides further support to the construct validity of the ESSQ-19. Items 2 and 3 of the ESSQ-19 ask about the impact of epilepsy surgery on specific aspects of seizures (ie, seizure-related injuries and postictal effects). Although seizure-free patients could have been instructed not to complete these two items, patient focus groups revealed that seizure-free patients valued being able to rate their satisfaction in these domains after being rendered seizure-free. Future studies will assess revised versions of the questionnaire excluding nonapplicable items, or revised scoring algorithms to account for skipping nonapplicable items.

The questionnaire posed little respondent burden, and there was a high completion rate across centers. The readability grade of the ESSQ-19 of the English version ranged from 8 to 10 for various items, which is higher than that usually recommended for the general public (grade 8). However, this grade should be easily understood by people aged 17 and 18 years, according to readability toolkits (https://www.webfx.com/tools/read-able/check.php), and is in line with broadly used treatment satisfaction questionnaire tools.[6]

### 4.1 | Limitations

A known limitation of measures of satisfaction, including patient satisfaction, is a positively skewed distribution of scores,

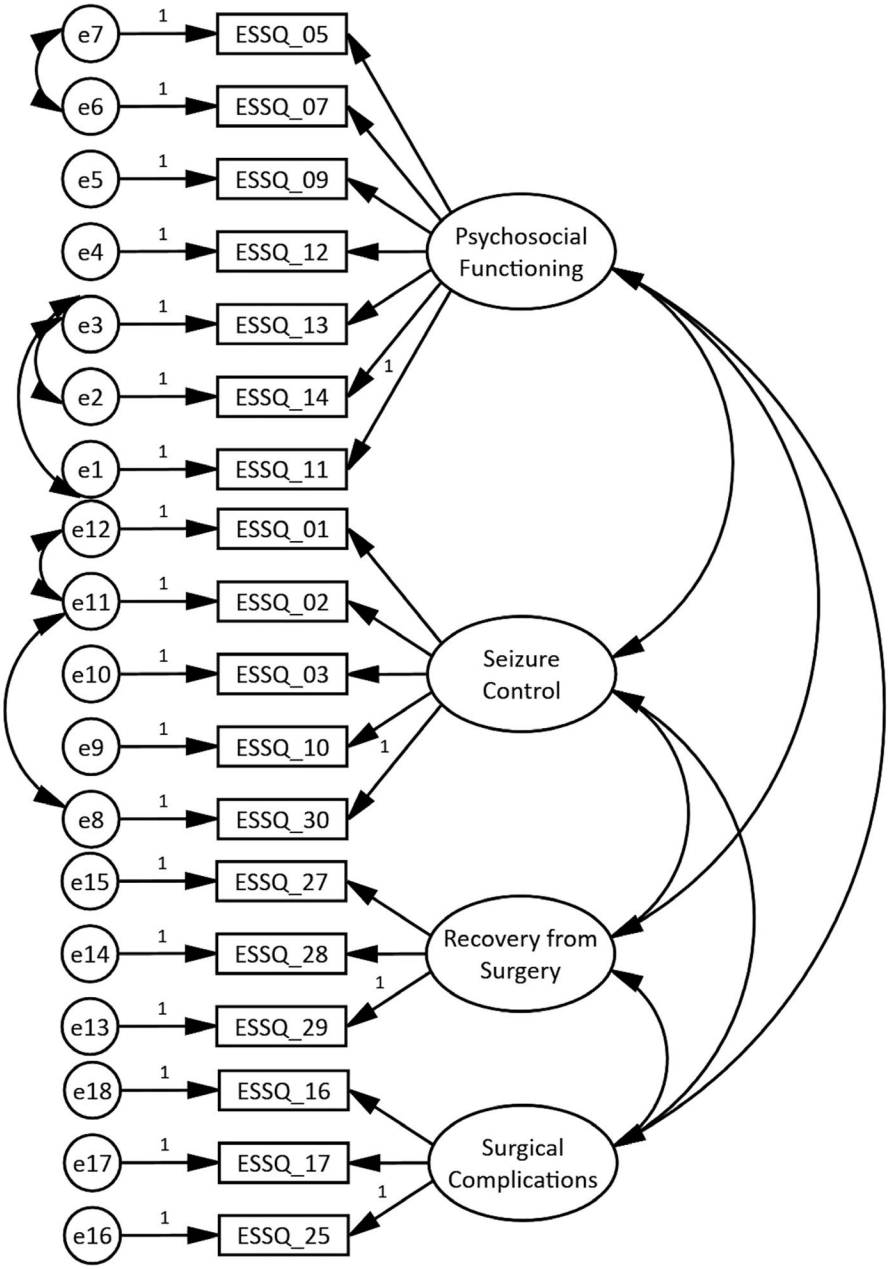


**FIGURE 1** Confirmatory factor analysis. Single arrows specify unidirectional relationships among variables. Double arrows specify bidirectional correlations (between error terms or between factors). e1-e18 represent unique variances that are not explained by the items; for example, the correlation between the error terms e6 and e7 is determined by the model's goodness of fit. ESSQ, Epilepsy Surgery Satisfaction Questionnaire

**TABLE 3** Internal consistency and test-retest reliability of ESSQ-19 domains and summary score

| ESSQ-19 domain and summary score | Mean (SD) | Cronbach alpha | Test-retest reliability, n = 192, ICC (95% CI) |
|---|---|---|---|
| Seizure control | 76.39 (25.02) | .94 | 0.85 (0.80-0.88) |
| Psychosocial functioning | 67.25 (26.07) | .95 | 0.84 (0.80-0.88) |
| Surgical complications | 84.00 (22.00) | .84 | 0.71 (0.63-0.77) |
| Recovery from surgery | 72.97 (24.35) | .90 | 0.79 (0.73-0.84) |
| Summary score | 73.53 (20.87) | — | 0.85 (0.80-0.88) |

Abbreviations: CI, confidence interval; ESSQ-19, 19-item Epilepsy Surgery Satisfaction Questionnaire; ICC, intraclass correlation coefficient.

in which respondents tend to rate items more favorably than unfavorably. In health care, the reasons are multiple and may include factors such as gratitude, faith, luck, and loyalty.[20] The experience with treatment satisfaction tools in epilepsy surgery and in other fields has been similar.[6,7] Measures to decrease the impact of positively skewed responses include

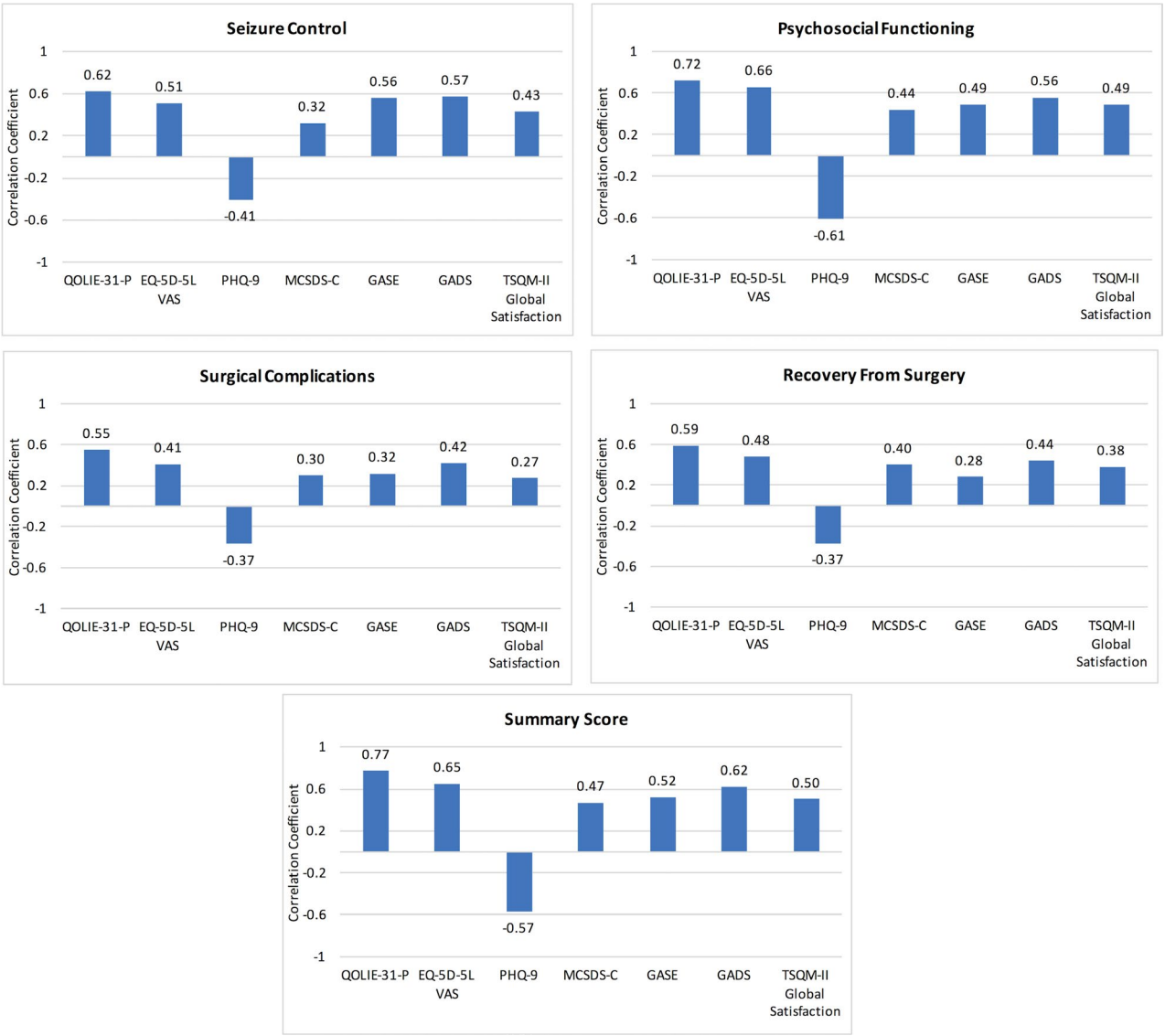


**FIGURE 2** Construct validity of the 19-item Epilepsy Surgery Satisfaction Questionnaire (ESSQ-19): correlations between the ESSQ-19 domains and summary score and various instruments. EQ-5D-5L VAS, EuroQOL five-dimension five-level visual analogue scale; GADS, Global Assessment of Disability for Seizure Disorders; GASE, Global Assessment of Severity of Epilepsy; MCSDS-C, Marlowe-Crowne Social Desirability Scale, Short Form C; PHQ-9, Patient Health Questionnaire; QOLIE-31-P, Patient-Weighted Quality of Life in Epilepsy; TSQM-II, Treatment Satisfaction Questionnaire for Medication–Version 2. Correlations with the PHQ-9 are negative because higher scores represent worse health (depression)

response options with nonneutral midpoints, resulting in a greater range of positive than negative response options.[6,21] Nonneutral midpoints were applied to the response options of the ESSQ-19, resulting in a less positively skewed response, as reflected by negligible ceiling effects of the summary score, and acceptable ceiling effects of all domains except surgical complications. A positive skew was unavoidable in assessing this domain, because the highest score corresponded to "no complications" and most patients did not experience complications. This initial validation study did not address a number of variables that may be important in relation to satisfaction with surgery. Future studies will assess the relationship between satisfaction with surgery and aspects such as burden of normality, ability to work, stigma, and specific psychiatric comorbidities. Further evaluation of the ESSQ-19 will be required to assess its ability to capture small but clinically important change and its performance in different patient populations.

## 4.2 | Clinical implications

The ESSQ-19 is a self-administered, brief, reliable, and valid instrument that fills a void in the area of patient-reported satisfaction with epilepsy surgery. The instrument has direct clinical utility to judge the success of surgical

interventions or surgical programs by providing patient-centered perspectives of satisfaction. It can also allow for a more nuanced discussion with the patient in the preoperative period about the role that complications and recovery have and how they can counterbalance the impact of seizure freedom or other outcomes. Hence, patients can make a better-informed decision using this point of care tool. Also, by identifying patient groups with different levels and determinants of satisfaction, clinicians can address these aspects specifically in individual patients. Lastly, as more surgical alternatives are introduced (eg, peripheral and central nervous system stimulation, focused ultrasound, laser therapy, and minimally invasive surgery), it will be important to assess and compare patient satisfaction with different surgical procedures.

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## CONFLICT OF INTEREST

S.Wi. has served as a consultant and received speaker and educational grant support from Eisai and UCB Pharma. D.K.N. has served as a consultant and received speaker and educational grant support from Eisai and UCB Pharma. All honoraria were donated to the Montreal University Health Center Foundation for epilepsy research. M.R.K. reports speaker and advisory fees for Eisai, Elsevier, Sunovion, Novartis, Sage Therapeutics, and UCB, unrestricted educational grants from UCB and Eisai, and research grants from UCB and Eisai. C.B.J. has received unrestricted educational grants from Eisai and UCB Canada for work unrelated to this project. None of the other authors has any conflict of interest to disclose.

## ETHICAL PUBLICATION STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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