



What Matters to You? Looking Beyond Seizure Freedom Following Epilepsy Surgery

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

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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 3 centers in Canada and one in Sweden. Participants also completed 7 validated questionnaires to assess construct validity. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) assessed the factorial structure of the questionnaire. Cronbach α 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 4 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 = .71-.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.

Commentary

My patients with epilepsy have taught me what having seizures feels like, and I try my best to understand. They try to tell me how taking anti-seizure medications feels and I listen. I get it, I will never understand the full experience. I try.

When seizures become refractory and we have the discussion about considering epilepsy surgery, I think we have pretty good arguments: The likelihood of seizure freedom or decreased seizure frequency, less medication and therefore fewer side effects, even the possibility of resuming social and economic activities our patients are not able to engage in while they have active seizures. A few times, however, my patients have let me know the real reason they want to undergo brain surgery and it ended being a reason I could not have imagined on my own. I had a patient who wanted to get a divorce but could only imagine being able to pursue this plan once she was not threatened by a possible seizure. I have a patient who wants to enter a live-in religious community but cannot do so with poorly controlled seizures. Faced with these questions I reflect with my patients that seizures are just a part of a more complex psychosocial situation derived from living with epilepsy. Then we discuss expectations and consider that even if seizures were to

be fully controlled, a lot of work would still be needed to address and achieve complex psychosocial goals. There are as many unique and personal reasons to consider epilepsy surgery as there are patients undergoing our complex evaluations, tests and procedures.

Currently, we only have limited tools to evaluate how successful we are in achieving satisfactory outcomes following epilepsy surgery. We are good at documenting and tracking seizure frequency,¹ seizure severity, amount of medication reduction or discontinuation² and measurable cognitive outcomes.³ What I am not sure we are doing is asking if our patients achieved the results they truly hoped for. We may forget to ask what matters to them, and if they got the result they were looking for once surgery is completed.

The highlighted work by Wiebe et al⁴ aimed to develop and validate a comprehensive tool to assess patient satisfaction following epilepsy surgery. Their work started by reviewing the available literature for reported subjective and objective measures of outcome, followed by conducting focus groups among epilepsy surgery patients and later consulting with experts in the field⁵ including neurologists, neurosurgeons and neuropsychologists. An initial 31 item questionnaire was administered twice (4-6 weeks apart) to 229 adults who had undergone





epilepsy surgery at least a year earlier. Higher correlation coefficients as well as expert assessment of clinically relevant information yielded 18 questions within 4 general domains: (1) seizure control, (2) psychosocial functioning, (3) surgical complications and (4) recovery from surgery. One more general satisfaction question was included to make a 19 item tool (ESSQ-19) which demonstrated good internal validity and test to test reliability. The group proposes this scale to the epilepsy community as an accurate, effective, and comprehensive way to evaluate surgical outcomes and patient satisfaction in a way that reflects the patient's physical function, goals, and overall experience. They postulate that an instrument designed to measure satisfaction may increase our understanding of patient-relevant outcomes, lead to better informed research, and improve patient counseling regarding surgical expectations.

Barriers to adoption of validated psychiatric or quality of life scales by clinicians include limited time and resources to administer the scales and deal with the possible consequences. The ESSQ-19 took participants, on average, 8 minutes to complete on their own, and patients reported no difficulties completing the task. It did require an approximately 8th-10th grade reading level, which may be a limitation for some patients.

The high prevalence of psychosocial co-morbidities in people with epilepsy (PWE) is well known. Diagnosing and treating depression and anxiety as part of the standard of care of PWE is fortunately more widely accepted today than in the past.⁶ The presence of psychiatric co-morbidities should not prevent or limit access to epilepsy surgery^{7,8} and furthermore the possibility of improvement in measures of depression and anxiety following epilepsy surgery⁹ is a further incentive to offer our patients a surgical option when indicated. Every time we ask about psychiatric co-morbidities and their complications, we need to be ready to deal with the answers. We need to be ready to support our PWE and psychiatric symptoms from the clinic. This may include psychiatric emergencies, such as active suicidal ideation.

Validated measures of quality of life, like the Quality of Life in Epilepsy Inventory (QOLIE-10) look beyond solely psychiatric co-morbidities and have shown a continuous tendency for improvement in quality of life years after epilepsy surgery,¹⁰ yet still do not capture items directly related to the surgery itself or the subsequent recovery. The authors of ESSQ-19 acknowledge that some important variables related to quality of life are yet to be integrated within this approach including ability to work and stigma.

Because satisfaction is so subjective, it may be difficult to measure objectively. When someone makes the decision to undergo elective resective brain surgery the stakes are so high that the conclusion on satisfaction seems like a self-fulfilling prophecy. Addressing satisfaction through a questionnaire makes the assessment more neutral and informs about the specific components that support overall satisfaction as an outcome to follow.

Thinking about the personal motivations that lead people to undergo epilepsy surgery led me to explore an international person-centered care movement geared to improve patient care partnerships and patients experience with the goal of improving patient care outcomes. This "What matters to you?" movement

is inspired by the principles of shared decision making.¹¹ Other initiatives have suggested including the patient's social and relational determinants to improve meaningful outcomes¹² in epilepsy surgery. I believe an approach of true patient-centered care discussions and shared decision making will result in better overall health and higher satisfaction both for patients and health care providers.

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References

1. Gracia CG, Chagin K, Kattan MW, et al. Predicting seizure freedom after epilepsy surgery, a challenge in clinical practice. *Epilepsy Behav.* 2019;95:124-130. doi:10.1016/j.yebeh.2019.03.047.
2. Lamberink HJ, Boshuisen K, Otte WM, Geleijns K, Braun KPJ. Individualized prediction of seizure relapse and outcomes following antiepileptic drug withdrawal after pediatric epilepsy surgery. *Epilepsia.* 2018;59(3):e28-e33. doi:10.1111/epi.14020.
3. Baxendale S. The cognitive costs, contraindications and complications of epilepsy surgery in adults. *Curr Opin Neurol.* 2020;33(2):207-212. doi:10.1097/WCO.0000000000000799.
4. Wiebe S, Wahby S, Lawal OA, et al. Development and validation of the epilepsy surgery satisfaction questionnaire (ESSQ-19). *Epilepsia.* 2020;61(12):2729-2738. doi:10.1111/epi.16709.
5. Lunney M, Wahby S, Sauro KM, et al. Patient satisfaction with epilepsy surgery: What is important to patients? *Epileptic Disord.* 2018;20(5):364-373. doi:10.1684/epd.2018.0995.
6. Bermeo-Ovalle A. Psychiatric comorbidities in epilepsy: We learned to recognize them; it is time to start treating them. *Epilepsy Curr.* 2016;16(4):270-272.
7. Altalib HH, Berg AT, Cong X, et al. Presurgical depression and anxiety are not associated with worse epilepsy surgery outcome five years postoperatively. *Epilepsy Behav.* 2018;83:7-12. doi:10.1016/j.yebeh.2018.01.040.
8. Patel S, Clancy M, Barry H, et al. Psychiatric and psychosocial morbidity 1 year after epilepsy surgery. *Ir J Psychol Med.* 2020;1-8. doi:10.1017/ipm.2020.114.
9. Devinsky O, Barr WB, Vickrey BG, et al. Changes in depression and anxiety after resective surgery for epilepsy. *Neurology.* 2005;65(11):1744-1749. doi:10.1212/01.wnl.0000187114.71524.c3.
10. Winslow J, Hu B, Tesar G, Jehi L. Longitudinal trajectory of quality of life and psychological outcomes following epilepsy surgery. *Epilepsy Behav.* 2020;111:107283. doi:10.1016/j.yebeh.2020.107283.
11. Barry MJ, Edgman-Levitan S. Shared decision making-pinnacle of patient-centered care. *N Engl J Med.* 2012;366(9):780-781. doi:10.1056/NEJMp1109283.
12. Shih P, Francis-Auton E, Nikpour A, Herkes G, Bleasel A, Rapport F. Enhancing quality of life among epilepsy surgery patients: Interlinking multiple social and relational determinants. *Epilepsy Behav.* 2020;102:106721. doi:10.1016/j.yebeh.2019.106721.