Original article

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Patient satisfaction with epilepsy surgery: what is important to patients?*

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ABSTRACT – *Aims.* Patient satisfaction with therapeutic interventions is an important outcome of care. Although generic measures of patient satisfaction exist, there is no validated scale for measuring patient satisfaction with epilepsy surgery. We aimed to systematically obtain patient-identified factors related to satisfaction with epilepsy surgery as a means of informing clinicians about the ways that patients evaluate outcomes of their treatment and as a conceptual basis for the future development of epilepsy surgery patient satisfaction scales. *Methods.* Focus group discussions with epilepsy surgery patients (n=9) were conducted to identify themes relevant to patient satisfaction with epilepsy surgery and to draft initial items of importance. Consensus methodology (Delphi technique) was used to obtain expert opinion (n=13) to refine the items. Member-checking with focus group participants was performed to ensure the identified items were relevant, clear, and inclusive. *Results.* A list of 31 items embodied 12 themes related to patient-reported satisfaction with epilepsy surgery. These included adverse effects, medical care or rehabilitation, seizure control, post-operative recovery, anti-seizure medication, independence, seizure worry, ability to drive, social relationships, self-confidence, improved cognitive function, and improved physical health. *Conclusions.* This study used a systematic approach to identify factors that are important to patients when assessing satisfaction with epilepsy surgery. This knowledge can assist clinicians caring for these patients and is also a critical step towards the validation of a formal scale to assess satisfaction with epilepsy surgery.

Key words: patient satisfaction, epilepsy surgery, questionnaire, patient-reported outcomes, thematic analysis, Delphi technique

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Surgery, in appropriately selected patients, is effective to control seizures in persons with epilepsy (Wiebe *et al*., 2001; Engel *et al*., 2012). However, due to the complexity of epilepsy, the overall outcome of epilepsy surgery includes more than seizure freedom (Wilson *et al*., 1999). Patient satisfaction with treatment reflects the level to which a patient is satisfied with outcomes of a specific treatment, rather than overall satisfaction with their care experience. Treatment satisfaction has been associated with important factors, such as quality of life (Malmgren *et al*., 1997) and adherence to treatment (Zyoud *et al*., 2013). While scales exist to measure patient satisfaction with medication (Atkinson *et al*., 2005), measuring patient satisfaction with surgery may address different domains and thus may require different instruments. Furthermore, condition-specific scales may have greater validity (Black, 2013) and responsiveness to change (Wiebe *et al*., 2003) than general scales. A tool developed specifically for epilepsy surgery may be most appropriate to measure patient satisfaction with this treatment.

Accurately measuring patient satisfaction with epilepsy surgery is challenging because of pre-operative and post-operative factors. A systematic review investigating patient satisfaction with all types of epilepsy surgery (Macrodimitris *et al*., 2011) showed an association with seizure freedom, mental health, employability, neurological deficits, and overall patient-reported quality of life. Four types of questions were generally used to assess satisfaction with epilepsy surgery (satisfaction/dissatisfaction, perceived success/failure, overall positive/negative impact, and willingness to repeat surgery or regretting surgery). Furthermore, the review suggested that pre-surgical factors such as memory deficits, patient expectations, or patient rationale for having surgery may also influence patient satisfaction with epilepsy surgery. Importantly, all tools for measuring patient satisfaction with epilepsy surgery identified in this review were single-item questionnaires, which did not appear to be developed with patient involvement or using a systematic approach.

Similarly, other publications that report on aspects of patient satisfaction with epilepsy surgery (Wass *et al*., 1996; Keene *et al*., 1998; Wheelock *et al*., 1998; Wilson *et al*., 1999; Reid *et al*., 2004; Chin *et al*., 2006; Dupont *et al*., 2006; Iachinski *et al*., 2014; Taft *et al*., 2014) used tools that did not appear to be created with input from patients. Therefore, our objective was to systematically derive a list of items, as the first phase of developing a future scale, that accurately conveys patient-reported satisfaction with epilepsy surgery by involving patients in the development of the questionnaire. These items can inform clinical care and can also be refined through psychometric evaluation to create a valid and reliable instrument to measure patient satisfaction with epilepsy surgery.

Materials and methods

We used a staged, systematic approach to derive items that are important for patients' satisfaction with epilepsy surgery (*figure 1*). Our team previously performed a systematic review of satisfaction with epilepsy surgery (Macrodimitris *et al*., 2011) that was used to guide the scope and methods of our study. Following the framework of Atkinson and Lennox (Atkinson and Lennox, 2006), a Multiple Cause Indicator model was selected as a conceptual framework for generating items, implying that patient satisfaction with epilepsy surgery is characterised by multiple, relatively independent, causes of satisfaction (Atkinson and Lennox, 2006). Focus group discussions with patients who previously underwent epilepsy surgery were conducted to identify themes relevant to treatment satisfaction. Focus group participants underwent epilepsy surgery in the single surgical centre in Calgary, Alberta that serves the entire province of Alberta (2015 population was 4,108,400), which is a single-payer organisation within a public healthcare system. Questionnaire items were generated based on these themes and a Delphi technique with experts was used to evaluate and refine items. Feedback from participants (member-checking) was sought to ensure the final questionnaire items were relevant, clear, and inclusive.

Focus groups

Focus group participants were recruited from outpatient clinics in the Calgary Comprehensive Epilepsy Program in Calgary, Alberta, Canada, from December 2014 to February 2015. A convenience sample was drawn from the surgical database. Participants were eligible to participate if they: were $\geq$18 years old at the time of their resective or disconnective epilepsy surgery (Calgary, Canada); had the capacity to provide consent; and were fluent in English (Grade 8 reading level). Patients who solely underwent diagnostic surgical procedures were excluded. Input from caregivers was obtained if required due to patients' limited ability to communicate.

Two discussion groups (k=2) were held. Discussions were exploratory, inductive, and content-driven and led by a trained facilitator (KMS) using eight open-ended questions (*table 1*). Each session was audio-recorded and notes were taken by a note-taker (ML). Focus group discussions concluded when content saturation was reached. Discussions were transcribed *ad verbum* into text following each session. Transcripts were thematically analysed using

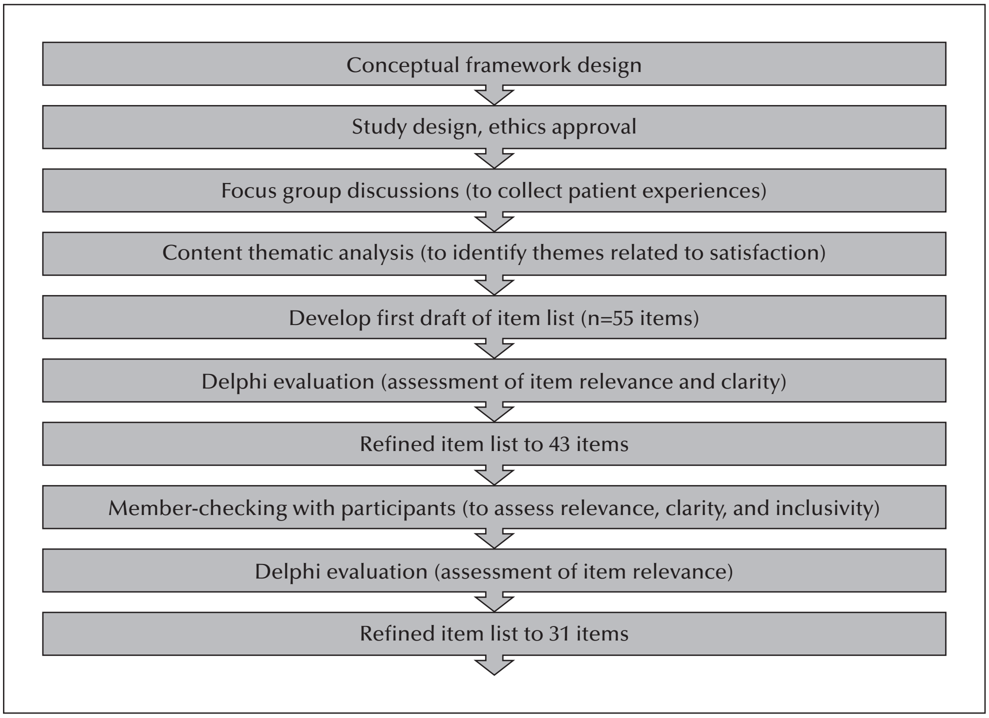

Figure 1. Stepwise approach in deriving the list of items.

Table 1. Open-ended questions used to guide the focus group discussions.

1. When you think about how satisfied or dissatisfied you are with epilepsy surgery, what things come to mind?
2. What are the good things about your outcome of epilepsy surgery?
3. What are the bad things about your outcome of epilepsy surgery?
4. Do you feel that your expectations of your surgery were met?
5. If you could go back in time, would you still choose to have your surgery?
6. Would you recommend the surgery to other people with epilepsy?
7. Do you have any worries about the effects of your surgery?
8. Was there anything about your surgery that you would change if you could?

both inductive and theoretical approaches (Braun and Clarke, 2006) to identify themes related to patient satisfaction.

Data analysis followed methods outlined by Braun and Clarke (2006). Transcripts were read repeatedly to familiarise the researcher (ML) with the content and categorised using codes derived from the data. Themes of patient satisfaction were identified from the codes, and frequency counts were generated for each category. Two researchers involved in the discussions (ML and KMS) agreed on the categories.

Item generation

Based on the themes identified in the focus group discussions, items were generated by the research team. A longer list of items was developed initially, with the goal of reducing irrelevant or unclear items to produce a shorter version without compromising content validity or generating double-barrelled questions.

Delphi evaluation (Round I)

In total, the Delphi panel consisted of 13 experts; five epileptologists with experience in dealing with surgical cases, two epilepsy neurosurgeons, two health service researchers focusing on epilepsy, two epilepsy psychologists, one epilepsy nurse, and one psychiatrist who was also an epidemiologist. Experts were purposively selected based on their expertise in epilepsy, neurosurgery, health services research, and scale design.

The first draft of items (*n*=55) and response options were circulated to experts for feedback to reduce the number of items on the questionnaire, to ensure that each item was relevant and that all domains were covered adequately. Items were phrased as questions and Delphi participants were asked to rate each item using a 5-point Likert type scale in terms of clarity (1=not clear and 5=very clear). Epileptologists and epilepsy neurosurgeons were additionally asked to rate each item on a 5-point scale in terms of relevance (1=not relevant and 5=highly relevant). Free text comments were also collected from all participants. A median relevance score of less than three was the cut-off for eliminating items and a median clarity score less than four was the cut-off for rephrasing items to improve clarity. Open-ended feedback guided the revision of the items with respect to phrasing or addition of items.

Member-checking with focus group participants

A subset of seven participants from both focus groups evaluated each item in the revised questionnaire for relevance/importance and clarity, using two 5-point scales (1=not at all important and 5=very important; and 1=not at all clear and 5=very clear). Items rated as "not at all important" by the majority were eliminated. Items were rephrased if more than one participant rated it as "not at all clear". This exercise ensured that items were unambiguous and comprehensible to the target population to establish face validity.

Delphi evaluation (Round II)

A final assessment of item importance was conducted using a similar Delphi technique. Seven participants, who also participated in Round I, were invited to participate based on their expertise in neurosurgery, epilepsy, statistics, epidemiology, and scale design. Experts were asked to identify redundant items that could be eliminated.

Ethics

This project was approved by the University of Calgary Conjoint Health Research Ethics Board (CHREB No. REB13-0882). Written informed consent was obtained from focus group participants.

Results

Focus groups

Characteristics of focus group participants are described in *table 2*. Group 1 had six participants of whom 50% were males. The second group contained three participants of whom one was male. Sessions lasted two hours and 1.5 hours, respectively. Patients represented a breadth of interventions and adverse outcomes, which ranged from mild (*e.g.* mood changes) to severe (*e.g.* hemiparesis). Seven participants (78%) were seizure-free at the time of interview. The median time since surgery was two years (interquartile range: 1.5-7.5). The age ranges for the first and second focus groups were 30-67 years and 38-64 years, respectively.

Open-coding analysis revealed 53 codes (comprising 12 unique themes) in the first session and 64 codes in the second session (constituting the same 12 themes identified in the first discussion). The number of participants that endorsed each theme is provided in *figure 2*. Additionally, while not directly measured, various levels of satisfaction were expressed during focus group discussions, suggesting that the groups represented diverse levels of satisfaction with surgery.

Item generation

Based on the themes generated, a team comprising a thematic analyst, an epileptologist, a statistician, and an expert in scale design agreed on the initial set of 55 items, which ensured that all themes were adequately captured. The items were then grouped by theme to present specific components of each (dis)satisfaction domain (*e.g.* headaches), as well as several general questions on the impact of surgery on overall quality of life and whether expectations of surgery were met.

Delphi evaluation (Round I)

Of the 55 items, 34 had a median relevance rating of 5, eight had a rating of 4.5, five had a rating of 4, five had a rating of 3.5, and three had a rating of 3. With respect to clarity, one item had a median rating of 5 and eight had a rating of 4.5. The majority (*n*=43) had a rating of 4. Two had a rating of 3.5 and one had a rating of 3 and was modified. No items had a clarity rating less than 3. The open-ended comments helped modify items to improve clarity.

Twelve items were removed from the initial 55-item questionnaire due to redundancy or poor clarity. The second draft consisted of 43 items, covering all themes and included global questions related to expectations of surgery, quality of life, and overall satisfaction with epilepsy surgery.

Member-checking with focus group participants

Four of the seven (57%) participants that received evaluations returned responses. Of the 43 items, none were rated as "not at all important" by the majority and thus none were eliminated. One item was rated as "not at all clear" by more than one participant. In consequence, this single item was rephrased to improve clarity.

Table 2. Characteristics of focus group participants.

	Focus group 1 (*n*=6)	**Focus group 2 (*n*=3)**
Age (years); mean		
At time of interview	45.7	50.0
At time of surgery	39.5	44.0
At epilepsy onset	21.0	2.0
Female, *n*	3	2
Time since surgery (years); mean	5.7	5.3
Number of AEDs; mean		
At time of interview	2.8	0.7
Total tried	6.7	8.3
Monthly seizure frequency; median		
At time of interview	0.0	0.0
Before surgery	23.0	4.0
Seizure freedom at time of interview; *n*	4	3
Complications of surgery; *n*		
Permanent	1	0
Transient	5	0
Patients with previous epilepsy surgery; *n*	1	0
Intracranial EEGs prior to surgery; *n*	3	1
Previous VNS; *n*	1	1
Aetiology; *n*[1]		
Hippocampal sclerosis	1	2
Cortical dysplasia	1	2
Low-grade tumour	2	0
Traumatic brain injury	3	1
Infection	0	1
Stroke	1	0
Topographies; *n*		
Temporal lobe	3	2
Frontal lobe	1	0
Supplementary sensory motor area	1	0
Multi-lobar	1	1
Surgical procedure; *n*[2]		
Cortical resection	3	0
Lobectomy	2	3
Amygdalohippocampectomy	3	2
Disconnection	0	1

[1] Some patients had more than one aetiology.
[2] More than one area of resection per patient.

Delphi evaluation (Round II)

Seven experts, that also participated in round I, were asked to provide input in the second Delphi round. Four had no additional comments and three (43%) provided feedback. The 43-item list was reduced to 31 items (*table 3*). Of the 12 items eliminated, eight were dropped due to the potential for recall bias regarding expectations of outcomes prior to surgery. Instead, a single item was devised that encompassed their

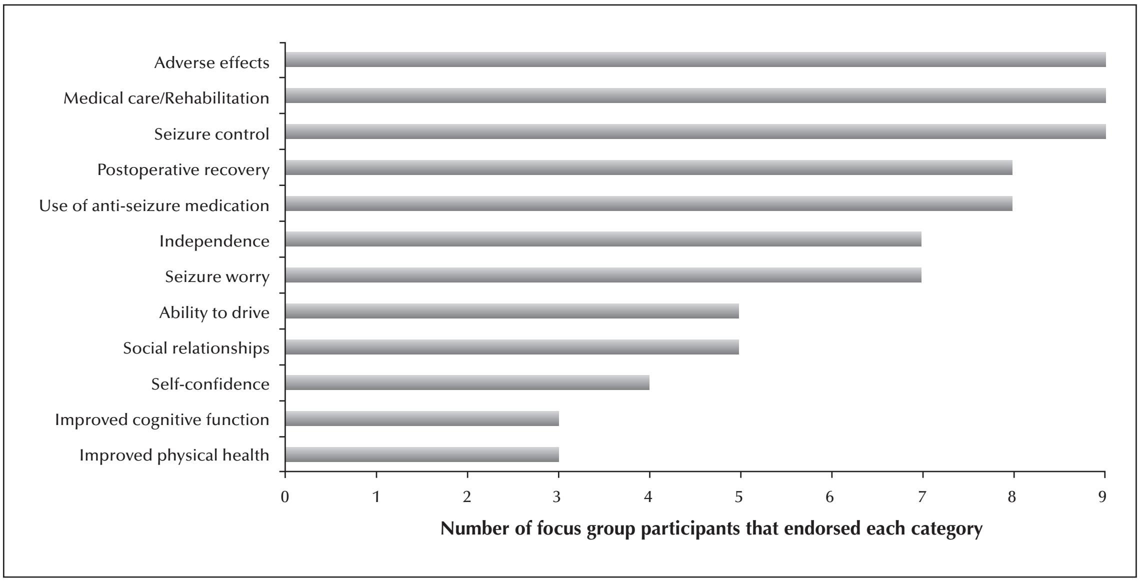

Figure 2. Frequency with which participants endorsed each category. The number of participants in the two focus groups was nine.

overall satisfaction with how epilepsy surgery met their expectations. Four items were omitted because they were deemed too similar to other items within the same theme, and one item was combined with another. Content validity of the 31-item list was maintained as each item addressed at least one of the themes, and all themes were covered by at least one item (*table 4*). Lastly, the readability of the 31 items was assessed using the Flesch-Kincaid readability test and matched a Grade 11 level.

Discussion

Using a systematic approach and standard methodology, we elicited aspects that are important to patients when assessing satisfaction with epilepsy surgery. A list of 31 specific items was derived.

Adverse effects of surgery, medical care or post-surgery rehabilitation, and seizure control were the most frequently endorsed themes. In addition to seizure freedom, being able to drive and reducing anti-seizure medications as a result of surgery were strongly expressed as a contributing factor of satisfaction. Impact of surgery on social relationships also influenced patients' satisfaction with surgery. Furthermore, an increase in self-confidence and independence, and a reduction in seizure worry also led to greater satisfaction. Adverse effects (related to mental or physical health), decreased cognitive function, delayed recovery, poor continuity of care, and low access to rehabilitation were described as contributing to greater dissatisfaction of surgery.

Importantly, this work aimed to identify factors relevant to patient satisfaction with therapeutic epilepsy surgery, and not satisfaction with the process of care. The latter focuses on a broader evaluation of the patients' experience with their care and has been found to be associated with provider empathy (Menendez *et al.*, 2015), communication (Birhanu *et al.*, 2010), and continuity of care (Fan *et al.*, 2005), among others. While our study did identify that medical care and rehabilitation are relevant to patient satisfaction with epilepsy surgery, in this context, these aspects of care are interventions that encompass the treatment and thus were included. Moreover, rehabilitation is associated with recovery from neurological deficits postoperatively, and therefore represents a different domain than simply process of care.

Patient satisfaction with treatment focuses specifically on the outcome of treatment and is constructed based on a patient's perception of the effectiveness, side effects, and convenience of the treatment (Atkinson *et al.*, 2005). Our focus group findings support the constructs of effectiveness of the surgery to reduce seizures and side effects (both physical and mental) as patients related these to their satisfaction with surgery. Convenience was de-emphasised in the focus groups. This could be because this domain is more relevant to treatment satisfaction with medication than with surgery (medication is administered chronically and frequently, whereas surgery is typically a single set of interventions), or because it is truly negligible in the face of the impact of surgery and its outcomes.

A study examining patient satisfaction with spine surgery identified patient age, body mass index (BMI), smoking status, and preoperative diagnosis as

Table 3. Thirty-one items to assess satisfaction with epilepsy surgery.

1. How satisfied are you with how epilepsy surgery affected your **seizure control**?
2. How satisfied are you with how epilepsy surgery **prevented accidents or injuries** caused by your seizures?
3. How satisfied are you with how epilepsy surgery affected **how you feel after a seizure**?
4. How satisfied are you with how epilepsy surgery affected the **amount of anti-seizure medication you take**?
5. How satisfied are you with how epilepsy surgery affected your **social life**?
6. How satisfied are you with how epilepsy surgery affected **whether you can hold a driver's license**?
7. How satisfied are you with how epilepsy surgery affected your **performance at work** (including domestic), **school,** or **volunteering**?
8. How satisfied are you with how epilepsy surgery affected your ability to participate in **leisure activities**?
9. How satisfied are you with how epilepsy surgery affected your **self-confidence**?
10. How satisfied are you with how epilepsy surgery affected how much you **worry about having a seizure**?
11. How satisfied are you with how epilepsy surgery affected your **cognitive function**, such as memory, ability to think, and speak clearly, *etc*.?
12. How satisfied are you with how epilepsy surgery affected your **mood**?
13. How satisfied are you with how epilepsy surgery affected your **overall physical health**?
14. How satisfied are you with how epilepsy surgery affected your **overall quality of life**?
15. How dissatisfied are you with **complications** that occurred during your epilepsy surgery?[1]

How dissatisfied are you with the following undesirable effects of epilepsy surgery[1]:

    16. Poor balance or coordination
    17. Muscle weakness
    18. Vision loss
    19. Memory loss
    20. Impaired speech or language
    21. Low mood
    22. Being irritable
    23. Poor physical health (*e.g.* headache, pain, fatigue, *etc.*)
    24. Decreased cognitive function (*e.g.* unable to think clearly)
    25. Decreased sensation (*e.g.* numbness)

26. How satisfied are you with the **tests you had**, such as MRI, brain scans, memory testing, seizure monitoring unit, *etc*.?
27. How satisfied are you with your **speed of recovery in hospital**?
28. How satisfied are you with your **recovery after discharge from the hospital (not including rehabilitation)**?
29. How satisfied are you with your **rehabilitation after discharge from the hospital**?[2]
30. How satisfied or dissatisfied are you with how epilepsy surgery met your expectations?
31. Taking into account all aspects of your epilepsy surgery, how satisfied or dissatisfied are you with your epilepsy surgery?

Example of response options for each item:
- *Extremely dissatisfied*
- *Very dissatisfied*
- *Dissatisfied*
- *Somewhat satisfied*
- *Satisfied*
- *Very satisfied*
- *Extremely satisfied*

Note these items are not yet validated for use as a satisfaction scale in clinical practice.

[1] Response options for these items were: Extremely dissatisfied; Very dissatisfied; Somewhat dissatisfied; Slightly dissatisfied; Not at all dissatisfied; Not applicable.

[2] Not applicable is included as a response option for this item.

statistically significant factors associated with patient satisfaction with treatment (Crawford *et al.*, 2017). Furthermore, the study found that, irrespective of pre-operative diagnosis, the mean change in functional health status and pain score was also significantly associated with patients' satisfaction level with treatment (Crawford *et al.*, 2017). While in our study, complications of surgery were mentioned by some participants as relevant to patient satisfaction, other research investigating factors associated with patient-reported satisfaction with spine surgery found that neither major nor minor complications were

Table 4. List of themes in the 31-item patient satisfaction with epilepsy surgery questionnaire. Each theme was represented by one or more questions.

Theme
Adverse effects
Medical care/ rehabilitation
Seizure control
Postoperative recovery
Use of anti-seizure medication
Independence
Seizure worry
Ability to drive
Social relationships
Self confidence
Improved cognitive function
Improved physical health
Quality of life *(global)* *
Expectations met *(global)**
Overall satisfaction *(global)* *

**Global* refers to a global single item addressing this domain.

significantly associated with satisfaction (Hamilton *et al.*, 2017). Further research currently ongoing will explore the relationship between surgical complications and patient satisfaction, which may be helpful to better understand patient satisfaction with surgery.

Our findings align with results of the systematic review of predictors of patient satisfaction with epilepsy surgery (Macrodimitris *et al.*, 2011). For example, seizure freedom, mental health, employability, neurological deficits, and overall quality of life were reported in the review (Macrodimitris *et al.*, 2011) and were also identified by the focus group participants in our study. However, an additional aspect of importance to patients is post-surgical rehabilitation, likely because of its association with recovery from neurological and cognitive postoperative deficits. This element is important to ensure that the overall goals of the treatment are sustainable and is an area that deserves further study.

Additionally, patients' expectations can determine their satisfaction with treatment (Bjertnaes *et al.*, 2012; Palazzo *et al.*, 2014). During the focus group discussions, when asked if their expectations had been met, there was mixed agreement among participants not only with respect to whether expectations were met but also whether they were properly explored and discussed prior to surgery. Ensuring patients have realistic expectations prior to receiving treatment may contribute to a greater level of satisfaction.

Not surprising, the themes identified in our research align with the domains of quality of life (QOL) scales. Previous research has also demonstrated a correlation between various aspects of quality of life and satisfaction with epilepsy surgery (Malmgren *et al.*, 1997). For example, in the quality of life in epilepsy scale (QOLIE-31) (Cramer *et al.*, 1998), many of the subscale domains (seizure worry, overall QOL, emotional well-being, energy and fatigue, as well as medication effects, work/driving/social limits, and cognitive functioning) were also identified in our research, suggesting a potentially strong correlation between quality of life and satisfaction with epilepsy surgery. Yet, tools that are used to assess satisfaction with surgery enable additional elements to be specifically considered, such as side effects of surgery and rehabilitation.

This work illustrates the complexity of patient satisfaction with treatment and demonstrates that patients evaluate treatment outcome considering many domains. In epilepsy surgery, while seizure freedom was expressed as highly relevant to satisfaction, other outcomes related to quality of life and other aspects of mental and physical health were also viewed as important to patients. Reducing anti-seizure medication following surgery was identified as related to satisfaction due to side effects and inconveniences of the medications. A better understanding of what is important to patients may guide physicians when communicating with patients and making decisions around treatment options. Furthermore, evaluating and monitoring patient satisfaction with surgery in practice is important for the healthcare system to drive quality improvement initiatives (Iannuzzi *et al.*, 2015).

Through patient focus group discussions and Delphi techniques, our study identified additional themes related to satisfaction, such as continuity of care and support during rehabilitation and recovery, independence, and social life. This is in contrast to the majority of published studies on patient satisfaction with treatment in which information was collected from patients using predefined questionnaires developed by the research team, and highlights the importance of involving patients when developing patient-reported outcome measures (Wiering *et al.*, 2017). We derived a list of items based on themes identified by patients who also re-evaluated the items to confirm their relevance and clarity. Our questionnaire is also comprehensive. Whilst shorter scales reduce completion burden and increase response rates, selecting a scale for content rather than brevity may be more informative (Rolstad *et al.*, 2011). Therefore, our goal was to maximise content validity by addressing each of the themes identified. An additional strength to this approach is that items were confirmed with patients following the focus group discussion, which supports content validity and relevance.

Despite these strengths, this study has limitations. We cannot rule out selection bias since it is possible that patients chose to participate because they were either extremely satisfied or extremely dissatisfied with their surgery. As well, seven of the nine patients were seizure-free at the time of the interview, which may under-represent patients with seizure relapse and could have skewed responses toward satisfaction with surgery. However, the importance of seizure control was universally endorsed and therefore the risk of under-representing this element of satisfaction with surgery seems minimal. Furthermore, the use of a Delphi panel of experts also guards against representing important issues in non-seizure-free patients. While not directly measured, a variety of levels of (dis)satisfaction were expressed during focus group discussions, further suggesting that groups were representative of various levels of satisfaction with surgery and that satisfaction is influenced by more than just seizure freedom. Only four of the nine focus group participants provided feedback on the drafted items. However, the missing opinions of these five participants were likely captured during the focus group discussions, as a summary of the discussion was agreed on during focus group discussions as a second measure of member-checking. Finally, focus group discussions were conducted in a single centre, thus potentially limiting external validity. However, it is anticipated that our results are applicable to other tertiary care centres in similar settings (for example, those with comparable socioeconomic and cultural characteristics).

In summary, thematic analysis revealed 12 patient-centred themes important for measuring patient satisfaction with epilepsy surgery. This work can inform both clinical care in epilepsy surgery and future studies designed to assess patient-reported outcomes in epilepsy surgery. Work is ongoing to develop an epilepsy surgery satisfaction scale using these items. ☐

Supplementary data.

Summary didactic slides are available on the www.epilepticdisorders.com website.

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TEST YOURSELF

(1) Why is patient-reported satisfaction with surgery important?

(2) What were the three themes of (dis)satisfaction with epilepsy surgery with the highest patient endorsement?

(3) What methods were used to devise the list of items to assess satisfaction with epilepsy surgery?

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".