



Balancing health literacy about epilepsy surgery in the community

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SUMMARY

Objective: Despite significant underutilization of surgical treatment for drug-resistant epilepsy, no studies have quantified patient desire for surgery within a representative population. The main objective was to determine desire for surgery in a sample with a high proportion of potential candidates to characterize patient-related barriers to the treatment. Secondary objectives included assessing clinical predictors of attitudes toward surgery and evaluating the impact of passive knowledge translation on desire for surgery.

Methods: An online survey was administered to all clients connected with a core epilepsy community access center. It obtained information about demographics, clinical characteristics, knowledge of epilepsy surgery, and interest in receiving surgery before and after receiving risk/benefit information about it.

Results: Of 118 potential respondents, 48 (41%) completed the questionnaire, of which 67% had failed more than two AEDs and 78% experienced seizures in the past year. Eleven (26%) were uninterested in receiving surgery at baseline, and this decreased significantly to 7 (16%) following knowledge translation regarding the benefits ($p = 0.001$). Significance was lost with subsequent complication rate information despite fewer respondents still being uninterested compared to baseline (20% vs. 26%). Having experienced seizures within the past month was correlated with being interested in or undecided regarding surgery at baseline and following all steps of knowledge translation. Subjects had conservative views regarding the benefits of surgery and largely overestimated the risks.

Significance: A significant portion of those with active epilepsy in the community do not desire surgical treatment. Passive knowledge translation regarding the risks and benefits enhanced optimistic attitudes and mobilized interest within a subset of participants. Preexisting views regarding the risks of surgery were exaggerated, and analysis suggests that these views can be modified with information about the benefits of surgery. However, exaggerated risk perceptions return following crude descriptions of the risks, underlying the importance of sensitive counseling from primary care physicians.

KEY WORDS: Epilepsy, Surgery, Attitudes toward health, Knowledge translation.



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The annual incidence of epilepsy is 50 cases per 100,000 in North America, and 5–10 per 1,000 live with

the condition.¹ One third are resistant to antiepileptic drugs (AEDs) and are therefore potential neurosurgical candidates.² Surgery for temporal lobe epilepsy (TLE) is highly successful, with three fourths of patients seizure-free after 1 year and more than two thirds after 10–20 years,^{3,4} with 90% of those receiving surgery being subjectively satisfied,^{5,6} most having an improved quality of life,^{3,5–7} and major complications being rare (2–3%).^{8,9} However, surgery is widely underutilized; <5% of eligible patients are treated and this rate has been decreasing over time.^{10–12} Many centers have

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increased the utilization of presurgical electroencephalography (EEG) assessments, but have not experienced a corresponding rise in surgery rates, suggesting that physician- and patient-related factors may affect whether patients receive surgical treatment.^{10,11} Neurologist-initiated referral for surgery is often delayed due to benefit underestimation and risk overestimation by the physician, with average time from onset to referral being 15–20 years.^{13–17} Patients also harbor unrealistic views, as three quarters consider surgery a last resort and 22% decline it when offered by a surgeon.^{18,19} These data are concerning, as recent literature reveals greater benefits in frontal and temporal lobe epilepsies with early surgical treatment.^{9,20,21}

Surveys that estimate patient desire for surgery have been poorly generalizable to potential surgical candidates with drug-resistant seizures. Prus & Grant²² found a 49% acceptance rate when guaranteed no residual seizures or deficits, an unrealistic representation of epilepsy counseling. More recently, 30% of the Italian Opinioni e Prassi nel Trattamento delle Epilessie Focali Farmacoeresistenti (OPTEFF) group study sample was interested in surgery, but this population had a low proportion of drug-resistant patients (only 35% had failed two or more AEDs), and were recruited from specialized epilepsy centers rather than community locations, which selects for high compliance.^{18,23–25} Accordingly, our study quantifies desire for surgery among patients who accessing services at a centralized community care access center, Epilepsy Halton Peel Hamilton (EHPH), that provides emotional and educational support to clients with epilepsy as well as advocates for patients by teaching epilepsy awareness to public servants. Clients span all stages of disease, but most are not adequately medically controlled and therefore require more social support. In this way, our population resembles drug-resistant potential surgical candidates.

The OPTEFF group utilized a brief and nonspecific educational survey-administered intervention stating that epilepsy surgery is not experimental and only performed if epileptogenic regions can be resected. Although 34% reported being more favorable toward surgery postintervention, the actual impact is unclear, as the investigators did not assess baseline desire, or whether more favorability meant newfound interest or simply less aversion. Almost all (96%) acknowledged requiring more concrete risk–benefit information before making a full decision.¹⁸ Therefore, our work determines the impact of risk–benefit information on attitudes toward surgery to identify subsets that may be mobilized with knowledge translation.

Finally, we show demographic and clinical factors that predict being interested in or undecided regarding surgery. These may guide future large-scale studies in comprehensively determining the interplay between predictors of desire for surgery, thereby influencing physician counseling techniques and decisions about allocation of health care system resources.

MATERIALS AND METHODS

Study population

The study protocol was approved by the University of Toronto Research Ethics Board. The population included all active clients of the EHPH agency, which represents the relatively recent unity of three prominent individual agencies in Halton, Peel, and Hamilton, with catchment areas in communities surrounding Toronto. Inclusion criteria limited the participants to those with a confirmed diagnosis of epilepsy. Potential participants who had not consented to be contacted for research purposes on initial contact with the agency (as per agency policy) were excluded. One's type of epilepsy or whether surgery was actually indicated did not affect selection, as understanding of attitudes in a community population was the intent. Because it was feasible to include all active clients (123), recruitment was complete rather than calculation based.

A link to the online SurveyMonkey (SurveyMonkey, Palo Alto, CA, U.S.A.) questionnaire was e-mailed to 123 potential agency clients with a description of the study and contact information for those who preferred to answer by phone or in-person.

Questionnaire

The 37-question survey was informed by prominent themes in the literature regarding attitudes toward epilepsy surgery,^{3–9,18,19} with additional input from both neurosurgical (Valiante) and community support perspectives (Milburn). EHPH staff with regular client contact made multiple revisions to the survey to ensure comprehension. There are no validated surveys to assess the desire for health care in epilepsy. Prior to receiving access to the questionnaire, respondents were required to read and agree to a consent form describing the nature of the study. Part one asked about demographics and social determinants of health (eight questions), severity of epilepsy (four questions), quality of life (three questions), utilization of health care resources (two questions), understanding of epilepsy, interest in surgical treatment, and attitudes toward the risks and benefits of surgery (15 questions). The second portion aimed to educate subjects with salient points regarding the risks and benefits, with subsequent reassessment of their interest in surgery. Accordingly, three questions provided specific evidence-based information about the rates of seizure freedom,^{3,4} patient satisfaction,^{5,6} and major complications.⁹ The questionnaire is available as Supporting Information.

Data analysis

Responses were analyzed with SPSS statistical software (IBM Corporation, Armonk, New York, USA), with outcomes expressed as frequencies and percentages. Each survey question was analyzed individually. Redundant response divisions were grouped. Data were presented in tables with notation of response rate and missing data.

A repeated-measures analysis of variance (ANOVA) compared cumulative interest in epilepsy surgery (across a consistent scale of Likert values) at baseline, after receiving information about patient satisfaction rates, after receiving further information about seizure freedom rates, and finally after receiving further information about complication rates. The Likert scale included a neutral reaction (undecided) and two paired positive and negative reactions (probably vs. probably not and definitely vs. definitely not). These were chosen over agree/disagree choices to ensure optimal comprehension of questions contributing to the primary outcome. Bonferroni corrected post hoc analyses compared each reassessment of desire to the baseline measure with significance set to $\alpha = 0.05$.

Assessment for predictors of attitude included six fundamental questions underlying the prominent themes in the literature: gender, level of education, most recent seizure, social supports, mindset regarding epilepsy surgery satisfaction rates, and mindset regarding surgery improving social acceptance.^{5,6,18,19} Education was excluded from analysis, as most were pediatric clients still attending school and so it did not actually measure health literacy and socioeconomic status. Chi-square statistics compared the group of interested/undecided clients to those who were uninterested by the above five factors, with significance set to $\alpha = 0.01$ (Bonferroni correction). Results were expressed as odds ratios (ORs) with 95% confidence intervals (CIs) and corresponding p-values.

RESULTS

Of 123 potential participants who were e-mailed the survey, three had inactive e-mail addresses and two had opted out of SurveyMonkey e-mails. Responses were provided by 48 participants (41%) over 2 months, and none initiated response by phone or in person.

Subject demographics and clinical characteristics

Demographic data summarized in Table 1 show that the majority of respondents were from well-educated households (76% with college or university), employed or at school full time (59%), and not receiving social assistance (76%). The study population was balanced in gender and across age and household income brackets.

Burden of disease is identified in Table 2, with most of the population having seizure onset during pediatric life (74% aged <18), seizure frequency of two or more within 1 year (78%), and seizures that were focal (47%). Two thirds have used three or more AEDs during the course of disease, and the same number are currently taking medications but not seizure-free. All patients had active epilepsy as defined by those either taking AEDs or having seizures within the preceding 5 years. By self-assessment, most respondents had a moderate quality of life (52%) and a sufficient/full understanding of the nature of their condition

Table 1. Demographics of the study population

	n	%
Gender ^a		
Male	22	46.8
Female	25	53.2
Age (years) ^a		
0–17	18	38.3
18–25	6	12.8
26–40	11	23.4
41–65	12	25.5
Household income (\$ CAN) ^b		
<40,000	11	25
40,000 – 69,999	5	11.4
70,000 – 99,999	12	27.3
≥100,000	16	36.4
Social assistance ^c		
Does not receive	34	75.6
Receives	11	24.4
Household education (highest achieved) ^c		
≤High school	6	13.3
Some college/university	5	11.1
Completed college/university ± graduate/professional	34	75.6
Employment status ^d		
Full-time work/school	27	58.7
Part-time work/school	4	8.7
Unemployed	15	32.6
Ethnicity ^a		
Caucasian/European	41	87.3
Asian	3	6.4
African American	2	4.3
Aboriginal	1	2.1
Immigration status ^a		
Lifelong Canadian	42	89.4
Self-identified immigrant	5	10.6
Missing data (response rate): ^a n = 1 (98%), ^b n = 4 (92%), ^c n = 3 (94%), ^d n = 2 (96%).		

(53%). The duration of disease is categorized by age of first seizure and current age, since all respondents had active epilepsy. The majority initially had pediatric onset but at the time of assessment for this study were either still at a short duration of disease (39%) or had moved into late adulthood (20%).

Attitudes toward receiving epilepsy surgery

Attitudes toward surgery were assessed by inquiring whether respondents would receive surgery for epilepsy if it were offered by a physician. Those who were either interested (probably or definitely) or undecided were combined for both data interpretation and predictor analysis (Table 4), as these views were considered “optimistic” and potentially responsive to in-depth risk–benefit counseling. In contrast, those inherently uninterested (probably or definitely) in surgery and nonresponsive to knowledge translation were labeled “uninterested.”

One half were initially undecided at baseline as shown in Table 3, with one fourth interested and the other fourth uninterested. After receiving information regarding the satisfaction and seizure freedom rates following epilepsy

Table 2. Epilepsy burden within the study population

	n	%
Age of first seizure (years)^a		
0–17	34	73.9
18–25	5	10.9
26–40	4	8.7
41–65	3	6.5
Most recent seizure^a		
1 month ago	24	52.2
1 month – <6 month ago	6	13
6 months – <1 year ago	6	13
1 year – <5 years ago	8	17.4
≥5 years ago	2	4.3
No. of seizures (in last 12 months)^a		
0	6	13
1	4	8.7
2–9	12	26.1
≥10	24	52.2
Seizure type (in last 12 months)^b		
None	4	8.5
Partial	22	46.8
Generalized	12	25.5
Unsure	9	19.1
No. of AEDs used (cumulative)^c		
1	8	17.8
2	7	15.6
3	8	17.8
≥4	22	48.9
Current AED use^c		
Uses AEDs, not seizure-free	29	64.4
Uses AEDs, seizure-free	10	22.2
Does not use AEDs	6	13.3
Active epilepsy (on AEDs or seizure <5 years ago)^c		
Yes	45	100
No	0	0
Quality of life (1 = “not so good” and 10 = “great”)^d		
1–4	4	9.1
5–7	23	52.3
8–10	17	38.7
Understanding of epilepsy^c		
Full	5	11.1
Sufficient	19	42.2
Good but lacking	12	26.7
Minimal	9	20
Duration of epilepsy (noted as: age of first seizure, current age)^a		
0–17, 0–17	18	39.1
0–17, 18–25	5	10.9
0–17, 26–40	9	19.6
0–17, 41–65	2	4.3
18–25, 18–25	1	2.2
18–25, 26–40	1	2.2
18–25, 41–65	3	6.5
26–40, 26–40	0	0
26–40, 41–65	4	8.7
41–65, 41–65	3	6.5
AED, anti-epileptic drug.		
Missing data (response rate): ^a n = 2 (96%), ^b n = 1 (98%), ^c n = 3 (94%), ^d n = 4 (92%).		

surgery, a smaller portion was uninterested in surgery (15% vs. 25%), and the relative proportion of those interested in surgery to those who were undecided also increased by a

factor of 1.7. Information about complication rates raised the number uninterested in surgery from that achieved after providing the seizure freedom data but not back to the baseline level (20% vs. 15%). Similarly, the relative proportion of interested versus undecided clients decreased by a factor of 1.1 with risk information, but was still 1.5 times greater than at baseline.

These variations in desire across the four assessments were statistically significant ($p = 0.002$). Post hoc analyses showed that the satisfaction and seizure freedom data significantly reduced the uninterested proportion compared to baseline ($p = 0.006$ and $p = 0.001$, respectively). The difference was no longer significant after receiving complication rate knowledge translation.

Predictors of attitudes toward epilepsy surgery

To determine predictors of attitudes toward surgery, optimistic respondents were compared to uninterested ones by the fundamental demographic, clinical, and mind-set factors shown in Table 4. Predictors of a baseline optimistic attitude included having a seizure within the past month (OR 22.2, 95% CI 2.5–200, $p = 0.001$), believing that most patients are satisfied with surgery (all optimistic, $p = 0.001$), and believing that most have improved social acceptance (all optimistic, $p = 0.008$). Data about the satisfaction and seizure freedom rates showed that the only predictor of an optimistic attitude was having a seizure within the past month (all optimistic, $p = 0.002$). Following the provision of information regarding surgical complication rates, having a seizure within the past month was still a predictor of optimistic attitudes (all optimistic, $p < 0.0005$), feeling that most are satisfied with surgery reemerged as a predictor (all optimistic, $p = 0.003$), and having good social support became a new predictor (OR 8.5, 95% CI 1.5–50, $p = 0.009$).

Pre-intervention knowledge of the purpose of epilepsy surgery and risk–benefit rates

A significant portion of the study population was neutral toward statements about the utility of epilepsy surgery and its benefits (Table 5). Less than 25% of respondents disagree with strong negative statements suggesting that surgery is dangerous, experimental, a last resort treatment, and leaves people as vegetables. Below 10% agree that prolonging time-to-surgery can reduce its impact on seizure burden and quality of life.

However, <10% disagree with statements about the positive effects of surgery, including those regarding seizure freedom, personal independence, work productivity, social acceptance, and relationship dynamics. Only one subject disagreed that most are satisfied with surgery.

A large proportion believes that focal neurologic deficits (75%), infection (63%), dependency (54%), and death (48%) are very or somewhat likely following surgery (Table 6).

Table 3. Attitudes towards epilepsy surgery, based on consecutive questioning progressing from left to right in the table below

	Baseline ^a n (%)	(+) Satisfaction data ^b n (%)	(+) Seizure freedom data ^b n (%)	(+) Complication data ^b n (%)
If offered, would you desire to receive surgery?				
Definitely	3 (7)	5 (11)	5 (11)	3 (7)
Probably	8 (19)	15 (33)	17 (38)	16 (36)
Undecided	21 (49)	17 (38)	16 (36)	17 (38)
Probably not	7 (16)	7 (16)	6 (13)	7 (16)
Definitely not	4 (9)	1 (2)	1 (2)	2 (4)
Repeated-measures analysis ^c				
p-Value*	0.002	–	–	–
Mean Likert				
Mean ± SE	3.02 ± 0.15	3.41 ± 0.15	3.48 ± 0.14	3.29 ± 0.15
Bonferroni post hoc analysis ^c				
p-Value* vs. baseline	–	0.006	0.001	0.285

* $\alpha = 0.05$, post hoc analysis corrected for multiple comparisons with Bonferroni correction.
Missing data (response rate): ^an = 5 (90%), ^bn = 3 (94%), ^cn = 6 (88%).

Table 4. Social and clinical predictors of attitudes towards epilepsy surgery

	Baseline			(+) Satisfaction and seizure freedom data			(+) Complication rate data		
	Interested/ undecided n (%)	Not interested n (%)	p-Value*	Interested/ undecided n (%)	Not interested n (%)	p-Value*	Interested/ undecided n (%)	Not interested n (%)	p-Value*
Gender									
Male	12 (63)	7 (37)	0.132 ^a	15 (71)	6 (29)	0.024 ^b	14 (67)	7 (33)	0.036 ^b
Female	20 (83)	4 (17)		23 (96)	1 (4)		22 (92)	2 (8)	
Most recent seizure									
<1 month ago	22 (96)	1 (4)	0.001^a	24 (100)	0 (0)	0.002^b	24 (100)	0 (0)	<0.0005^b
≥1 month ago	10 (50)	10 (50)		14 (67)	7 (33)		12 (57)	9 (43)	
Quality of social support received									
Significant	27 (77)	8 (23)	0.581 ^c	32 (87)	5 (14)	0.318 ^d	32 (87)	5 (14)	0.009^d
Minimal	4 (67)	2 (33)		5 (71)	2 (29)		3 (43)	4 (57)	
Most are satisfied with surgery									
Agree	18 (100)	0 (0)	0.001^e	19 (100)	0 (0)	0.012 ^d	19 (100)	0 (0)	0.003^d
Neutral/disagree	13 (54)	11 (46)		18 (72)	7 (28)		16 (64)	9 (36)	
Surgery improves social acceptance									
Agree	14 (100)	0 (0)	0.008^a	15 (94)	1 (6)	0.201 ^b	15 (94)	1 (6)	0.087 ^b
Neutral/disagree	18 (62)	11 (38)		23 (79)	6 (21)		21 (72)	8 (28)	

* $\alpha = 0.01$, corrected for multiple comparisons. Bolded p-values indicate statistical significance.
Missing data (response rate): ^an = 5 (90%), ^bn = 3 (94%), ^cn = 7 (85%), ^dn = 4 (92%), ^en = 6 (88%).

DISCUSSION

Despite overwhelming evidence of the success of epilepsy surgery and its superiority over continued AED use in drug-resistant epilepsy,^{3–9,20} it remains significantly underutilized: only a small proportion of potential candidates receive surgery.^{10–12} To aid in resource allocation and improve utilization, a current province-wide goal in Ontario, Canada,¹² it will be important to understand

patient-related barriers to surgery and the impact of passive information about the risks and benefits on desire for surgery.

Those with undecided interest in surgery were considered optimistic and open-minded regarding the treatment modality with the potential to respond to physician counseling. Therefore, undecided and interested clients were combined into an “optimistic” group for interpretation and analysis of predictors of attitudes. This cohort was

Table 5. Knowledge of the effectiveness of epilepsy surgery

	Strongly agree n (%)	Agree n (%)	Neutral n (%)	Disagree n (%)	Strongly disagree n (%)
Knowledge "Epilepsy surgery. . ."					
Is dangerous ^a	1 (2)	13 (28)	27 (59)	3 (7)	2 (4)
Is experimental ^a	1 (2)	9 (20)	25 (54)	9 (20)	2 (4)
Is a last resort treatment ^b	9 (20)	12 (27)	19 (42)	4 (9)	1 (2)
Leaves people as vegetables ^b	1 (2)	4 (9)	29 (64)	9 (20)	2 (4)
Is less effective if excessively delayed ^a	1 (2)	3 (7)	30 (65)	10 (22)	2 (4)
Benefits "Epilepsy surgery. . ."					
Can effect seizure freedom ^b	5 (11)	10 (22)	26 (58)	3 (7)	1 (2)
Increases one's independence ^a	6 (13)	12 (26)	25 (54)	2 (4)	1 (2)
Increases work productivity ^b	6 (13)	14 (31)	22 (49)	1 (2)	2 (4)
Enhances one's social acceptance ^a	6 (13)	10 (22)	26 (57)	3 (7)	1 (2)
Enhances one's relationships ^a	7 (15)	5 (11)	31 (67)	2 (4)	1 (2)
Is satisfying to most who receive it ^b	8 (18)	11 (24)	25 (52)	1 (2)	0 (0)
Missing data (response rate): ^a n = 2 (96%), ^b n = 3 (94%).					

Table 6. Impression of the risk for complications following epilepsy surgery

	Very likely n (%)	Somewhat likely n (%)	Somewhat unlikely n (%)	Very unlikely n (%)
Likelihood of major complications				
Focal neurological deficits ^a	3 (7)	30 (68)	10 (23)	1 (2)
Infection ^a	1 (2)	27 (61)	10 (23)	6 (14)
Becoming dependent ^a	1 (2)	23 (52)	15 (34)	5 (11)
Death ^a	1 (2)	20 (46)	16 (36)	7 (16)
Missing data (response rate): ^a n = 4 (92%).				

compared to those who were uninterested before, or despite, receiving risk–benefit information. Of clients associated with the EHPH community care access center, 26% were uninterested in receiving surgery at baseline and two thirds of optimistic patients were undecided. Following information about rates of seizure freedom and patient satisfaction following surgery, the uninterested proportion decreased by 40% (16% vs. 26%, $p = 0.001$) and optimistic clients became more interested by a factor of 1.7. After receiving risk rate information, the uninterested portion increased toward but not back to baseline (20% vs. 26%), and those with optimistic views became mildly less favorable. Despite lower uninterest and higher optimism after complete knowledge translation, the difference was not significant compared to baseline. The potential to mobilize epilepsy patients with passive knowledge translation seen here, along with greater uninterest after crude descriptions of risk, emphasizes the importance of in-depth physician counseling about the risks and benefits of surgery. With only 26% averse to surgery at baseline,

expansions in resources will likely be met with interest from patients.

Predictors of preintervention optimistic attitudes were based on seizure burden (recent seizures) and mindsets about surgical impacts (feeling that most recipients are satisfied and experienced improved social acceptance). Following knowledge translation about the benefits of surgery, seizure burden was the only remaining predictor of having an interested or undecided attitude, and preexisting mindsets no longer had a significant impact. This difference suggests that preexisting beliefs about the utility of epilepsy surgery were not firm and that mindsets did respond to new information, underlying the importance of early and comprehensive counseling by referring physicians. Seizure burden remained as a predictor after receiving the complication rate data, and mindsets regarding satisfaction rates reemerged as a predictor of attitudes, suggesting that crude descriptions of the risks of surgery without patient-specific counseling may reignite preexisting biases.

Extended predictor analyses (data not shown) with regrouping of responses showed that reallocating undecided clients to the uninterested group (interested vs. undecided + uninterested) removed significance for all predictors in Table 4. The mindset that surgery improves acceptance did emerge as a predictor of interest after step 3 of knowledge translation. Secondly, when excluding undecided clients (interested vs. uninterested) all predictors shown in Table 4 remain except for quality of social support after step 3 of knowledge translation. Belief that most are satisfied with surgery emerged as a new predictor of interest after step 2 of knowledge translation. This analysis strengthens the a priori decision that undecided patients are more similar to interested than uninterested ones. This is likely due to a more open-minded attitude and suggests that they may potentially also respond to comprehensive risk/benefit counseling.

Unfortunately though, the recruitment method did not allow for a large enough sample size to perform multiple analyses of sufficient power. The predictor data presented here should therefore be considered as pilot data revealing important themes that require further large-scale analysis to confirm. They are intended to serve as a basis for the development of more comprehensive knowledge translation techniques for future work.

In addition, we show that people with epilepsy are largely aware of the benefits of surgery but have poor knowledge of its utility, and highly overestimate its complication rates. More than 90% of clients agreed with, or were neutral toward, the ideas that most are satisfied with surgery, surgery induces seizure freedom, and surgery enhances quality of life. Although more than half self-assessed their understanding of epilepsy treatment as full or sufficient, less than one fourth disagree that epilepsy surgery is experimental, leaves people disabled, is dangerous, and is a last resort treatment. Between one half to three fourths of clients believe that death and major complications are very or somewhat likely, which is not a trivial misunderstanding, as the true rates are 0% and <5%, respectively.^{8,9} This further underscores the need for in-depth patient counseling to ensure informed decision making.

The tendency to refuse epilepsy surgery is higher within our community access center population compared to those accessing services at the epilepsy centers surveyed by the OPTEFF group (25% vs. 13%). This difference is not due to a higher rate of uncertainty within OPTEFF respondents (47% vs. 49%), but likely results from the preferential selection of compliant patients attending specialized epilepsy clinics over those in the community as shown in other populations.^{23–25} Our community care access center recruits had a significantly higher proportion of therapy resistance, with two or more failed AEDs (67% vs. 35%), and of patients having seizures within the last year (78% vs. 45%), suggesting it is representative of drug-resistant potential surgical candidates. Because seizure burden correlated with an optimistic attitude toward surgery here, assessment in populations with a low burden may underestimate both desire for surgery and the impact of knowledge translation.

The relative ease of changing attitude following passive knowledge translation suggests that respondents had not received sufficient information from their AED prescriber, which is consistent with studies of neurologist risk overestimation and referral delay.^{13–17} Because risk–benefit information is important for patient decision making, it is crucial for primary epilepsy care providers to adequately describe the impacts of surgery before or when patients become drug resistant. It is notable that the purpose of this study was not to advise that a similar knowledge translation technique with written information be used in clinical practice, but rather to determine whether views were malleable to serve as a basis for further development of active techniques based on two-way interaction. Studies show

that patients require specific risk–benefit information relevant to their life and clinical experience, which suggests that patients are frequently hyperresponsive to risk information, interventions will require multiple discussions over time and many reassessments of the longevity of the knowledge translation effect.^{18,26,27} This approach would likely accentuate the effect of benefit information seen here and alleviate the negative impact of crude risk information.

There is an increased benefit to early surgery for frontal and temporal lobe epilepsies, and so prompt counseling and referral is especially important in patients with these types of epilepsy.^{20,21} Our sample contains two major subsets of patients based on disease duration: those with pediatric onset currently having a short duration of disease who are ideal counseling targets, and those with early onset now in adult life. Careful consideration of parent–child decision-making dynamics will be important, because most have onset during childhood when parents have a greater impact on treatment decisions. It may be important for future work to establish age-specific predictors so that physicians can counsel both patients and parents accordingly.

The study population was recruited from a Canadian community care access center, and so the attitudes seen may have been influenced by the health care system in Canada. The time to diagnosis and the proportion of patients residing in the community may be specific to the Canadian public system and wait times within it. Furthermore, in Ontario, Canada, there are current initiatives to increase funding for epilepsy presurgical assessment facilities, and so the results may be particularly relevant to guide resource allocation in this system. Although it will be important for further studies to assess the impact of risk–benefit information on desire for epilepsy surgery within the American system, studies have found similar physician- and patient-related barriers to prompt care as well as low uptake rates across the United States.^{10,11,15–17,22}

This study was limited by the data collection method employed, as e-mail-delivered surveys have poorer response rates due to the lack of interpersonal contact and perception as junk mail. Our 41% response rate is in line with that of previous studies showing rates from 18% to 50% among online surveys.^{28,29} This method prevented the determination of whether responders differed from nonresponders, but studies show no difference when nonresponders have preconfirmed access to Internet, as was true for our study.^{30–32} Potential respondents were also offered the option of responding by phone or in person to prevent sample biasing, although none responded via offline means.

Our cohort had greater severity of epilepsy than the overall epilepsy population and data on nonrespondents was not available. This was intended in order to select those that resemble potential surgical candidates. It is not fully clear

whether this happened because drug-resistant patients have a greater need for community support or because they were more likely to respond to the survey, but previous studies have shown that the former is true and at least partially responsible.^{23–25} On the other hand, our population consisted of a high proportion of patients who are educated, young, and not receiving disability, which was unexpected based on recruitment in community access centers. These factors may be expected to affect interest in surgery. The methodology prevented definite ascertainment of whether this was due to preferential representation of these patients within the community access center or only within those who responded to the survey, although the experience of EHPH staff suggests that these are characteristics common to the majority of clients. However, it is still unclear whether these results are translatable to epilepsy patients who are undereducated, older, and receiving disability. It may be important for future work to consider other means of reaching patients in the community, including recruitment in family health teams or family practice locations that have more balanced representation. This would also allow for a multisite recruitment with more power than the single agency recruitment here.

The proportion who would receive surgery without further counseling was significantly greater than the number who actually receive surgery (26% vs. <5%), with an even greater discrepancy when including those who are mobilized with specific information about the benefits of surgery (49% vs. <5%).¹² Therefore, resource expansion initiatives to increase assessment for surgical candidacy, such as those in progress in Ontario, Canada, will likely be met with interest from patients.¹²

CONCLUSIONS

Our community-based assessment of people with epilepsy has revealed that those with a high seizure burden and rate of AED failure largely overestimate the risks of surgery and are generally neutral toward the benefits. One fourth of this population is uninterested in receiving surgery, whereas the remaining portion is considered optimistic and either interested (one fourth) or undecided (one half). Predictors of an optimistic attitude are greater seizure burden and positive mindsets about the effectiveness of surgical intervention. Providing passive written information from the literature about the benefits of surgery to people with epilepsy reduced the proportion that was uninterested in surgery and prompted a subgroup to reallocate from being undecided to being interested in surgery, although this effect was no longer significant after the subjects were advised about surgical risk rates. This study assesses desire for surgery in a population with a high number of treatment-resistant potential surgical candidates and determines the impact of passive risk–benefit counseling. Current levels of interest greatly exceed the rate of surgical treatment, so future initiatives to

increase presurgical assessment capacity and improve physician referral should be pursued.

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DISCLOSURE

None of the authors have any conflict of interest to disclose. 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 in the online version of this article:

Figure S1. Study questionnaire with response frequencies.