



Survey of epilepsy and seizure awareness in Manitoba: An evaluation

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ABSTRACT

Background: Epilepsy and seizure awareness is gradually improving across Canada. With the strategic proposal for a Comprehensive Epilepsy Program in Manitoba (including formation of a new Pediatric Epilepsy Monitoring Unit (EMU)), a provincial strategy has been recommended outlining a path towards improved access to epilepsy care. We sought to qualify the current state of clinician knowledge and comfort towards diagnosis and management of this condition.

Methods: A qualitative online survey (Survey of Epilepsy and Seizure Awareness in Manitoba: An Evaluation (SESAME)), comprised of 36 short-answer questions, was delivered to primary care and specialist physicians in Manitoba.

Results: One hundred and eight subjects responded across varying medical disciplines. One hundred and one (93.5%) had previously managed patients with epilepsy, and 87 (80.6%) had previously ordered an electroencephalogram (EEG). A total of 63 (59.4%) had referred to a neurologist, with a lower proportion (30, 28.3%) referring specifically to an epileptologist. Only 36 respondents (33.3%) had heard of the International League Against Epilepsy (ILAE) guidelines. A total of 61 (56.5%) were unaware of invasive EEG techniques. Most (85, 78.7%) understood a role for surgery in treating epilepsy, with 12 (11.1%) unaware of surgical therapies beyond vagal nerve stimulation (VNS). Finally, less than half (44.2%) had heard about the Comprehensive Epilepsy Program in Manitoba, with nearly two-thirds (62.8%) indicating that they would like to have more information on epilepsy management.

Conclusions: The SESAME successfully identified strong awareness towards epilepsy, with identifiable lapses in knowledge that will benefit from a formal provincial-wide educational curriculum.

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1. Introduction

Epilepsy affects approximately 1 in 26 individuals, with a prevalence of nearly 220,000 patients with epileptic seizures in Canada (and an incidence of nearly 42 individuals newly diagnosed per day) [1]. Of these, 60–70% will be successfully treated with medications while the remaining 20–40% will experience ongoing seizures that fail to respond to medical therapy alone [2,3]. For this latter group of patients with 'medically refractory' epilepsy, additional testing and surgical intervention are now known to offer the greatest chance for seizure control in the long-term [4], by identifying a possible seizure focus for resection or disconnection.

Fortunately, epilepsy and seizure awareness within the medical community is gradually improving across Canada. In part, these efforts have been bolstered by advances in Ontario, which now has a formal set of guidelines for the development and coordination of provincial

epilepsy monitoring units (EMUs) [5]. Such initiatives have been additionally supported by cost-effective economic analyses stemming from improved access to epilepsy surgery in Ontario, which has garnered further support at the local and provincial level [6]. These developments coincide with the increasingly widespread implementation of formal guidelines from the International League Against Epilepsy (ILAE), advocating for earlier referrals for patients whose seizures fail as few as two antiepileptic medication trials, for the consideration of surgical evaluation [7]. The ILAE has also recognized that the primary goal of treatment for epilepsy is seizure freedom. Nevertheless, a significant proportion of frontline epilepsy care providers in Canada remain unaware of the current trends in the treatment of refractory epilepsy. Primary care providers and specialists continue to have misperceptions about the disease, its implications, potential work-up studies, and even current treatment paradigms for this condition. This is particularly true in underserved communities or regions, such as in Manitoba, where specialist availability and local infrastructure support for epilepsy care have been limited.

With the aspiration of creating a Comprehensive Epilepsy Program in Manitoba [including recent completion of a new Pediatric EMU,

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which began seeing patients in late 2017], a provincial strategy has now been proposed outlining a path towards improved access to epilepsy care. In the context of advancing care for children and adults with epilepsy in the province, we sought to qualify the current state of clinician awareness (including trends and attitudes towards medically refractory epilepsy, indications for referral and its treatment) among primary care providers and specialists in Manitoba. Through this survey, our goal was to identify specific gaps in clinician knowledge and/or awareness that may be targeted through intervention and/or education, to more effectively elevate the standard of epilepsy care being delivered across the province. To the best of our knowledge, this is the first survey of its kind in Manitoba, capturing the breadth of epilepsy awareness among practicing physicians in the province.

2. Materials and methods

This ‘Survey of Epilepsy and Seizure Awareness in Manitoba: An Evaluation’ (SESAME) study was approved by the University of Manitoba Human Research Ethics Board and the Health Sciences Centre Research Review Committee. A confidential, standardized, and anonymized survey comprised of 36 short-answer questions was delivered electronically to primary care and specialist physicians in Manitoba. To be eligible, participants had to be medical doctors licensed under the College of Physicians and Surgeons of Manitoba. Questions for the survey were generated on the basis of comparable community surveys that have already been validated and published in the literature, and an attempt was made to collate three separate surveys into a single survey tool, without duplication of questions [8–10]. General demographic data were collected anonymously (including participants’ age, gender, specialty, and duration of practice), and focused questions were aimed at evaluating awareness regarding current definitions of epilepsy, indications for referral to an epilepsy specialist, and knowledge of surgical treatment options. Specific attention was given to record results from neurologists and non-neurologists, with the basic assumption that the former comprises a study group who would be expected to have a higher level of awareness of epilepsy, given their focused training. The questionnaire was delivered by the office of the Winnipeg Regional Health Authority (WRHA) via an up-to-date physician mailing list that reaches all physicians currently practicing within the WRHA (i.e., within Winnipeg and Churchill), including both academic and rural settings. The questionnaire was comprised of an online survey that was hosted by the ‘Survey Monkey’ platform. Following an initial mass email, a second survey attempt was conducted one month later and again, at three months, to seek out an increased response rate from physicians who had not yet responded. Out of 2249 physicians contacted to participate in the SESAME study, a total of 108 individuals (4.8%) responded.

Data from each respondent were tabulated for the full study cohort. Continuous variables were described as mean and standard error of the mean (SEM). Categorical variables were described as the number of participants who answered ‘yes’ to each question and the associated percentage. Summary statistics were calculated based on nonmissing values. Of note, given the categorical nature of data recorded, and because of the small sample size, *p* values were not calculated on the data presented herein.

3. Results

A total of 108 physicians completed the SESAME. The average age of respondents was 44.4 years old (± 1.0 year), with 41% of respondents being female (Table 1). With respect to respondents’ self-reported specialization and practice details, there was a strong representation from each of the following disciplines: pediatrics (27, 25.0%), internal medicine (21, 19.4%), psychiatry (17, 15.7%), emergency medicine (14, 13.0%), neurology (11, 10.1%), and family medicine (10, 9.3%). Specialists from anesthesia, medical genetics, ophthalmology, public health

Table 1

| | |
|-----------------------------|----------------|
| Physicians screened — no. | 2928 |
| Physicians enrolled — no. | 108 |
| Age — years (\pm years) | 44 (± 1) |
| Male sex — no. (%) | 64 (59.3%) |
| Years in practice — no. (%) | |
| <3 years | 26 (24.1%) |
| 3–5 years | 14 (13.0%) |
| 6–9 years | 11 (10.2%) |
| 10+ years | 57 (52.8%) |

Continue variables expressed as mean (SEM); categorical variables as expressed as (%).

and preventative medicine, radiology, clinical health psychology, and the clinical assistant program comprised the remaining 8 respondents (7.4%). The majority of respondents (57, 52.8%) reported having been in practice for over 10 years, and 26 (24.1%) reported practicing medicine for less than 3 years (Fig. 1).

The SESAME posed specific questions regarding epilepsy diagnosis and management. A total of 36 respondents (33.3%), with 11 (out of 11) neurologists (100%) and 25 (out of 97) non-neurologists (25.8%), reported having heard of the ILAE guidelines for defining medically intractable epilepsy (Table 2). Moreover, 24 (out of the 68) participants who had treated epilepsy (35.3%) acknowledged refractory epilepsy to be defined by the failure of appropriate, informative trials of two antiepileptic medications. Another 43 (out of 68) respondents (63.2%) considered refractory epilepsy to be defined by a failure of at least three (and up to ten or more) antiepileptic medications. Of those polled, a total of 101 (out of 108) respondents (93.5%), including 9 (out of 11) neurologists (81.8%) and 92 (out of 97) non-neurologists (94.9%), had previously diagnosed patients as having epilepsy. Overall, 80 of all respondents (74.1%), including 11 neurologists (100%) and 69 (out of 97) non-neurologists (71.1%), had previously treated patients with epilepsy in their practice. In regard to the volume of patients with epilepsy managed, the majority of respondents (74 out of 108, 68.5%) reported treating between one and ten patients with epilepsy or seizure disorders per month.

Of all 68 respondents who reported having treated patients with epilepsy, 40 (58.8%) considered epilepsy to be medically intractable when appropriately selected medication at full doses failed to stop seizures. In contrast, 47 (69.1%) considered epilepsy to be medically intractable when appropriately selected medications at full doses failed to reduce seizures. Additionally, 38 (55.9%) considered epilepsy to be medically intractable when their patients experienced intolerant side effects from antiepileptic medications.

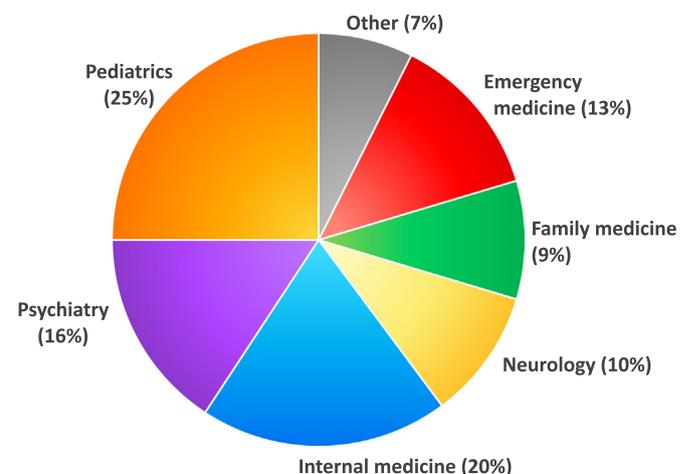


Fig. 1.

Table 2

| Category of assessment | Question posed | Neurologists | Non-neurologists |
|--------------------------------------|--|---|---|
| | | No. responded yes/total no. responded (%) | No. responded yes/total no. responded (%) |
| General | Diagnosed epilepsy | 9/11 (81.8%) | 92/97 (94.9%) |
| | Treated epilepsy | 11/11 (100%) | 69/97 (71.1%) |
| Referrals | Previous patient referral to neurologist | 0/11 (0%) | 63/97 (65%) |
| | Previous patient referral to epileptologist | 9/11 (81.8%) | 21/97 (21.7%) |
| | Previous referral for EEG monitoring | 11/11 (100%) | 76/97 (78.4%) |
| | Previous referral for video-EEG monitoring | 10/11 (90.9%) | 26/97 (26.8%) |
| | Previous referral for epilepsy surgery | 8/10 (80%) | 6/58 (10.3%) |
| Awareness of current ILAE guidelines | Aware of ILAE guideline | 11/11 (100%) | 25/97 (25.8%) |
| | Aware of ILAE drug guidelines | 9/10 (90%) | 15/58 (25.9%) |
| | Aware of invasive EEG monitoring | 9/11 (81.8%) | 38/97 (39.2%) |
| | Aware of epilepsy surgery | 11/11 (100%) | 74/97 (76.3%) |
| Epilepsy training | Previous access to epilepsy training | 11/11 (100%) | 75/79 (94.9%) |
| | Interest in further epilepsy training | 2/7 (28.6%) | 52/79 (65.8%) |
| | Awareness of Manitoba's Comprehensive Epilepsy Program (CEP) | 6/7 (85.7%) | 32/79 (40.5%) |

A total of 63 respondents (59.4%) indicated previously referring patients with epilepsy to a general neurologist, with fewer (30, 28.3%) reporting referrals specifically to an epileptologist (i.e., a neurologist specializing in epilepsy). In regard to diagnostic investigations and imaging for epilepsy, 87 (out of 108) participants (80.6%), including 11 neurologists (100%) and 76 (out of 97) non-neurologists (78.4%), had reported ordering electroencephalograms (EEGs) for patients with seizures and/or epilepsy, and 36 respondents (33.3%) – specifically 10 neurologists (90.9%) and 26 non-neurologists (26.8%) – had reported formally referring patients to an epileptologist for the purpose of their patients receiving video-EEG telemetry in the EMU for seizures and/or epilepsy. A total of 61 respondents (56.5%) were unaware of invasive EEG techniques, and while most (85, 78.7%) understood a role for surgery in treating epilepsy, 12 (11.1%) were unaware of any additional surgical therapies beyond vagal nerve stimulation (VNS). Of those who had previously treated patients with epilepsy, 14 participants (20.6%), i.e., 8 neurologists (80%) and 6 non-neurologists (10.3%), had reported referring these patients for surgical evaluation and/or management.

Eighty-five (78.7%) of respondents, i.e., 11 neurologists (100%) and 74 non-neurologists (76.3%), acknowledged that there was a role for surgical intervention in treating medically intractable epilepsy. Moreover, 19 participants (17.6%) were unaware of any surgical techniques for epilepsy, including VNS. Overall, 82 physicians (95.4%) reported having access to information dealing with epilepsy during their professional training, but 54 (62.8%) stated that they would like to have more information on epilepsy and seizure management. Only 38 respondents (44.2%) reported being aware of the Comprehensive Epilepsy Program, including the new Pediatric EMU, currently underway at Health Sciences Centre/Children's Hospital, University of Manitoba in Winnipeg.

4. Discussion

Epilepsy is a chronic neurological condition characterized by recurrent seizures. Epilepsy can present at any age, but the majority of new diagnoses (~85%) arise in childhood with a second peak in late adulthood. In fact, the incidence of epilepsy is higher in children, with a higher prevalence of epilepsy in adult patients. In North America, approximately 1 in 26 individuals will be diagnosed with epilepsy in their lifetime, making it the 4th most common neurological disorder [11]. In fact, 1 in 10 of all people will have at least one seizure in their lifetime, affecting up to 130,000 Manitobans. In Manitoba, given a population of ~1.34 million, there are between 6700 and 20,100 patients with epilepsy (based on cited prevalence rates of 0.5–1.5%) [12–16]. Overall, anywhere between 20 and 40% of individuals have refractory epilepsy and may be eligible for surgical evaluation, requiring admission to an EMU [17,18]. Of these, anywhere between 1.5% and 40% (i.e., between 100 and 2500 patients, depending on the literature) will

require invasive EEG monitoring with intracranial electrodes, with as high as 80% (over 5000 patients) who stand to benefit from some form of surgical intervention for this condition [15,19,20]. Additionally, the burden of untreated epilepsy is even higher when one factors in expenses stemming from recurring emergency department visits (contributing to the issue of longer wait times and fewer resources in the emergency room), lengthy hospital admissions (with prolonged bed occupancies), costly admissions to intensive care units, costly hospital-to-hospital transfers for complex care, repeat imaging studies (and specifically, magnetic resonance imaging wait times), medication-related expenses, mental health-related costs (secondary to depression, psychosis, etc.), and productivity losses.

The conventional first attempt at treatment for epilepsy is medication. Typically, the seizures in two-thirds of patients with epilepsy will respond to one or two antiepileptic medications. However, the remaining one-third are considered patients with treatment-refractory seizures and are therefore potential candidates who may benefit from surgery. The ILAE recommends prompt referral to an epilepsy center to assess for a potential surgical candidacy in these patients with treatment-refractory seizures. These recommendations reflect extensive outcome studies in the literature that cite substantially improved seizure-free outcomes following resective surgery [4]. This is further supported by a vast multitude of scientific studies reporting substantially higher rates of seizure freedom and low risks associated with these procedures. Postsurgical results are favorable to the extent that the literature states that 'epilepsy surgery remains the most underutilized of all accepted medical interventions' [21,22]. In temporal lobe epilepsy, seizure freedom rates are as high as 70–85% following surgical resection, in comparison with 5–10% seizure freedom rates on continued medical therapy for those whose epilepsy demonstrates drug resistance [4,23]. The surgical advantage persists throughout the patient's lifetime, with at least 60–75% of patients with temporal lobe epilepsy free of seizures ten years postsurgical intervention [24]. Similar success can be seen in extratemporal lobe epilepsy. While extratemporal lobe epilepsy poses higher challenges in terms of localizing a seizure focus, it can still be successfully treated with rates as high as 50–70%, if not higher. Even catastrophic epilepsies (characterized by unilateral seizure events confined to one hemisphere with seizures numbering in the dozens to hundreds per day) can show tremendous benefit with hemispherectomy procedures, which offer seizure freedom rates as high as 70–90% in some studies.

Seizure freedom is important, as the risk of morbidity is fourfold higher for patients with epilepsy, with a 12% chance for death from all-causes within the first 2 years of diagnosis [25,26]. Moreover, 'sudden unexplained death in epilepsy' or 'SUDEP', has a mortality risk of ~1%/year and poses a significant and cumulative threat to younger patients with inadequately controlled seizures [27]. Hence, the ILAE recommends earlier referrals for surgery, ideally in the pediatric cohort

and in young adults. This approach offers the highest chance for seizure freedom (i.e., “cure” if seizure freedom is life-long), allowing patients the opportunity to complete their education, pursue employment opportunities, engage socially, continue driving, and overall, maintain a sense of independence. Adults with longstanding epilepsy may also accrue multiple related medical problems, including depression and/or psychosis, in addition to accumulating the burden of side effects related to lifelong treatment with antiepileptic medication. In many instances, these patients have difficulty retaining employment and/or are increasingly dependent on others for their care. Epilepsy, therefore, poses significant impacts and productivity losses not only at the individual level, but at the family, community, and societal scales, also.

Extending beyond productivity losses, epilepsy surgery has also been shown to be more cost-effective than continued medical therapies, with epilepsy surgery significantly improving patient's quality of life by mitigating ongoing, devastating side effects associated with long-term medical therapy. According to a recent cost-effectiveness study in Ontario [6], surgery emerged as the dominant strategy over continued medical therapy in patients with treatment-refractory seizures, with surgery being less costly and providing better clinical benefit, overall. Specifically, epilepsy surgery provided good value for money invested over a twenty-year period, with incremental cost-effectiveness ratios ranging between \$25,020 and \$69,451 per quality-adjusted life year (QALY). Moreover, despite recent medical cutbacks in Ontario, the proven cost-effectiveness of a comprehensive epilepsy program has resulted in continued support and growth of such a program. Similar studies report comparable findings, with cost-effectiveness ratios ranging between \$15,581 and \$27,200/QALY, in favor of epilepsy surgery versus continued medical management [28,29]. In fact, it has been postulated that the direct and total cumulative costs associated with continued medical management begin to exceed those of surgical intervention anywhere between 3 and 8 years [30,31]. Additionally, yearly productivity losses associated with epilepsy are estimated to be \$6484 USD (or \$8557 CAD) per individual with epilepsy [32]. In Manitoba, assuming that roughly half of the population with epilepsy are adults (i.e., ~9500 patients), this corresponds to ~\$81.3 million CAD.

In the last two years, great strides have been taken towards the formation of a formal Comprehensive Epilepsy Program at the University of Manitoba, including the development of a state-of-the-art, two-bed Pediatric EMU. Additional recruitments have led to a faculty roster comprised of three adult and two pediatric epileptologists, along with a fellowship-trained epilepsy neurosurgeon well-versed in invasive monitoring and resective techniques for epilepsy in children and adults. A bi-monthly, multidisciplinary Refractory Epilepsy Conference is now regularly held in conjunction with colleagues from radiology, nuclear medicine, neuropsychology, and pathology, with open invitation to nurses, EEG technologists, residents, fellows, and medical students, where challenging cases may be reviewed for surgical candidacy. Over thirty surgical cases have now been performed over the past two years, including two hemispherectomies, with excellent seizure-free results. A provincial-wide proposal is currently under review for upgrading the Adult EMU to a four-bed capacity, which will additionally increase throughput for adult patients with epilepsy in the province.

In the context of these advances, it is timely that a survey tool (SESAME) be developed and implemented to assess physician knowledge and awareness towards epilepsy in the province. Future efforts towards developing educational resources may be focused towards topics or concepts not otherwise well understood by the general medical community. Based on the SESAME's results, 100% of participating neurologists showed excellent proficiency and awareness towards epilepsy management and diagnosis (as expected), with substantially lower rates (nearly 25%) reported in non-neurologists (including family physicians, pediatricians, and emergency physicians, among other disciplines). Only one-third (33.3%) of respondents showed awareness towards the more recent ILAE guidelines, including the definition of medically refractory epilepsy. Interestingly, less than two-thirds of

respondents (59.4%) reported referring patients with epilepsy to a general neurologist, with nearly 80% (78.7%) indicating an understanding for the role of surgery in treating epilepsy. Nevertheless, just over one-half (56.5%) of participants were aware of invasive EEG techniques, and one-tenth (11.1%) were unaware of surgical options beyond VNS. In fact, a comparable number (17.6%) were unaware of any surgical techniques for epilepsy (including VNS). Although less than half (44.2%) of respondents had heard about the Comprehensive Epilepsy Program at the University of Manitoba, nearly two-thirds (62.8%) indicated that they would like to have more information on epilepsy and seizure management. Similar results are reported in other comparable surveys, including a focused Canadian survey in 2014 on neurologists' awareness of the recommended standards of practice for epilepsy surgery; in this study, 48.6% of respondents did not know the definition of drug-resistant epilepsy while 75% of neurologists identified inadequate healthcare resources as the greatest barrier to surgery for patients with epilepsy [10].

From a program development standpoint, the information acquired through this qualitative survey was helpful in steering a direction towards raising epilepsy awareness in non-neurologist practitioners in the Province of Manitoba. This group would include family physicians, general pediatricians, psychologists, emergency physicians and internists, among others, in the hopes of further educating this important, often first-line group of physicians who are bound to encounter patients with epilepsy in their practice. Efforts tackling this barrier would include offering CME-based lectures, webinars, and other teaching symposia to medical groups, including physicians, nurses, and other support workers. The preparation of educational material (flyers, pamphlets, etc.) would also be helpful and could be distributed to healthcare professionals' offices, in addition to other community-based groups. Additionally, Manitoba benefits from a nonprofit, community-based resource, the 'Epilepsy and Seizure Association of Manitoba,' whose goal is to promote the well-being of patients with epilepsy/seizure disorders [33]. These advances underscore the need for more education and awareness in the community at large. Moreover, there are important lessons to be drawn from the Ontario experience, which has developed an innovative provincial program named 'Project ECHO,' geared towards establishing satellite referral centers in peripheral communities ('spokes') that refer into resource-intensive 'hubs' capable of providing more advanced epilepsy management and education [5,34]. Helpful technologies including remote EEG and imaging data access, along with improved teleconferencing capabilities, are rapidly changing the management of complex medical patients spanning large, underserved, geographic regions and have, therefore, garnered the attention of provincial health leadership in Manitoba. The combination of raising epilepsy education and awareness in the healthcare and patient community, combined with innovative solutions aimed at assessment and treatment of a challenging patient population spanning a large geographic region, will serve as the next future steps towards building a Comprehensive Provincial Program in Manitoba.

This study had a few important limitations worth outlining. This survey captured an extremely low rate of responders (4.8%) out of all contacted physicians, compared with other, larger qualitative surveys in the literature whose response rates have ranged between 20% and 66% [8–10]. Although low response rates are typical of qualitative surveys such as the one used here, it is surmised that our response rate was low because of a combination of lack of physician interest, busy schedules, and certain specialties where epilepsy is rarely encountered. The Manitoba Physician directory does report on the specialty of some, but not all physicians – making further interpretation challenging in this regard. Additionally, electronic surveys may be discarded or readily missed; to counter this, the survey was distributed three times (i.e., initially, and then at 1 and 3 months subsequent to the initial send-out), which helped to achieve a slightly higher response rate. Nevertheless, continued efforts to improve these rates could be bolstered by sending out prestamped mail-based surveys, among other initiatives.

5. Conclusions

With the imminent creation of a Comprehensive Epilepsy Program in Manitoba, a provincial strategy has now been proposed outlining a path towards improved access to epilepsy care. Using a survey tool, we sought to qualify the current state of clinician awareness, including trends and attitudes towards medically refractory epilepsy, indications for referral, and its treatment among primary care providers and specialists in Manitoba. The SESAME identified that although neurologist awareness towards epilepsy remains strong, non-neurologists will benefit from educational efforts focusing on the ILAE guidelines, indications for referral, and discussion regarding surgical options for epilepsy management. To the best of our knowledge, this is the first survey of its kind in Manitoba capturing the breadth of epilepsy awareness among practicing physicians in the province. These results will be used to guide the development of a formal, provincial-wide educational curriculum focusing on epilepsy management and treatment.

Disclosures

The authors have no conflicts of interest to declare.

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