

OHTAC Recommendation: Care for Drug-Refractory Epilepsy in Ontario

Ontario Health Technology Advisory Committee

July 2012

Background

During an evidence review of brain imaging technology (magnetoencephalography [MEG]) ([Functional Brain Imaging](#)), the Ontario Health Technology Advisory Committee (OHTAC) became aware of the fact that epilepsy surgery is an effective technology for people with epilepsy refractory to drug treatment.

In the process of determining the number of patients to whom this technology may apply, the Medical Advisory Secretariat, the predecessor of Health Quality Ontario, identified the following preliminary statistics:

- Only about 2% of Ontario patients eligible for epilepsy surgery receive the surgery, which is similar to other jurisdictions.
- Significant wait times (greater than 1 year) are associated with obtaining diagnostic testing to determine eligibility for surgery.

As a result, OHTAC recommended a field evaluation to further explore the role of MEG in Ontario and the barriers to access to epilepsy surgery in the province ([OHTAC Recommendation, Functional Brain Imaging](#)). This study was undertaken by the Programs for Assessment of Technology in Health (PATH). Based on its report back to OHTAC ([PATH Field Evaluation](#)), PATH requested the creation of a Provincial Epilepsy Strategy Working Group that would include representation from all epilepsy centres in the province to

- determine the prevalence of drug-refractory (also known as medically refractory) epilepsy in Ontario;
- identify the barriers to access to epilepsy surgery in the province; and
- recommend strategies to improve diagnosis times and epilepsy surgery wait times for eligible surgical candidates across Ontario.

The working group, formed in February 2011, created a guidance document outlining potential strategies to increase access and standardize care for people with epilepsy in Ontario, including issues related to surgical treatment of epilepsy (Appendix 2).

The working group report was presented to OHTAC in March 2011 and spurred the creation of an OHTAC Expert Panel on a Provincial Strategy for Epilepsy Care that was asked to

- provide a report on the current state of care for drug-refractory epilepsy in Ontario and major issues concerning epilepsy care in Ontario, and
- form recommendations for a provincial strategy for epilepsy care in Ontario.

This report (Appendix 3) formed the basis of this public engagement initiative.

Decision Determinants

A decision-making framework has been developed by OHTAC that consists of 7 guiding principles for decision making, and a decision-making tool called the Decision Determinants tool. (Table 1) When making a decision, OHTAC considers 4 explicit main criteria: overall clinical benefit, value for money, feasibility of adoption into health system, and consistency with expected societal and ethical values. For more information on the Decision-Making Framework, please refer to the *Decision Determinants Guidance Document* (http://www.health.gov.on.ca/english/providers/program/mas/pub/guide_decision.pdf).

A summary of the Decision Determinants can be viewed in Appendix 1.

Based on the Decision Determinants criteria, OHTAC weighed in favour of increasing the capacity for the management of epilepsy in Ontario. High quality evidence indicates that epilepsy surgery significantly reduces seizure frequency among those who have drug-refractory epilepsy, thus improving their quality of life and decreasing the burden on the health care system.

OHTAC Recommendation

The evidence is convincing that epilepsy surgery for drug-refractory epilepsy for adults and children is highly effective at eliminating or reducing the frequency of seizures. Furthermore, epilepsy surgery is cost-effective, and the cost-effectiveness improves over the long term and would be even more favourable if the analysis was done from a societal perspective that considers indirect costs, lost productivity, caregiver burden, etc. Evidence also demonstrates that an integrated epilepsy program that provides both medical and surgical management is also cost-effective in the long term. Despite this evidence, less than 2% of patients who might benefit from epilepsy surgery do so because of the lack of a systematic approach to this problem.

- The Ontario Health Technology Advisory Committee (OHTAC) therefore recommends that the report of the Expert Panel on a Provincial Strategy for Epilepsy Care on improving access to the necessary diagnostic testing for surgical candidacy for epilepsy surgery be used as a resource in developing a provincial approach to addressing this issue.

OHTAC further endorses the accompanying economic analysis on costing and the high-level implementation plan from the report.

Appendix 1 – Decision Determinants

Table 1. Decision Determinants for Epilepsy Care

Decision Criteria	Sub Criteria	Decision Determinants Considerations
Overall clinical benefit	Effectiveness	There is high quality evidence that epilepsy surgery is effective at reducing seizure frequency. Two randomized controlled trials compared surgery to no surgery in patients with drug-refractory epilepsy. Both demonstrated significant reductions in seizure frequency.
	Safety	There are some complications associated with epilepsy surgery. In the published literature identified, we observed a 0.1% mortality rate associated with the surgery.
	Burden of illness	An estimated 20,000 Ontarians have drug-refractory epilepsy.
	Need	Between 1%–2% of patients eligible for epilepsy surgery currently undergo the procedure.
Consistency with societal/ethical values	Societal and ethical values	Patients with epilepsy are more likely to suffer from social isolation and other mental illnesses, and they are less likely to be able to work.
Value for money	Economic evaluation	ICER for children with drug-refractory epilepsy \$25,000–\$69,000 (Cdn)/QALY. Societal costs (time off work for caregivers, inability to work, social isolation, etc.) were not factored into the economic analysis.
Feasibility of adoption	Organizational feasibility	Please see appendices for description of provincial strategy for epilepsy care in Ontario.

Abbreviations: ICER, incremental cost-effectiveness ratio; QALY, quality-adjusted life year; RCT, randomized controlled trial.

Appendix 2

Epilepsy Surgery in Ontario: Increasing Access and Standardizing Care (March 2011)

Following the presentation of the field evaluation results examining the use of magnetoencephalography (MEG) in determining surgery candidacy in children with drug-refractory epilepsy (also known as medically refractory epilepsy), the OHTAC requested further information on 3 aspects of epilepsy care and epilepsy surgery:

- an estimate of prevalence of medically refractory epilepsy,
- identification and framing of the system-wide issues related to epilepsy care and surgery, and
- how to shorten the time to diagnosis and improve access to surgery.

An epilepsy strategy working group was formed to provide a provincial perspective and to compile province-wide data at both pediatric and adult centres of care. The working group was made up of 22 representatives from all of the epilepsy centres in the province: The Hospital for Sick Children (HSC); Children's Hospital at London Health Sciences Centre; McMaster Children's Hospital and the Children's Hospital of Eastern Ontario; London Health Sciences Centre; University Health Network, Toronto Western Hospital; and Hamilton Health Sciences, Hamilton General. The following text summarizes the information gathered and consensus obtained by the working group in response to OHTAC's request.

Prevalence of Medically Refractory Epilepsy in Ontario

Epilepsy affects 5 in every 1,000 people (95% confidence interval, 4.2–6.1) in Ontario and 4 to 5 children and adolescents per 1,000, with an incidence of 30 to 60 new diagnoses per 100,000 individuals each year. Incorporating these Ontario-based prevalence estimates with 2006 Canadian Census data, there are about 65,000 Ontarians (10,000 children and 55,000 adults) with epilepsy (not including Aboriginal people with epilepsy). Of these, about one-third (20,000 people) do not respond to drug therapy and require further evaluation to determine which treatment options, including surgical intervention, are available to them. Not all individuals will be surgery candidates, with about one-third of this group (6,800 patients) having medically refractory epilepsy that is not amenable to surgical intervention. However, determining noncandidacy in refractory patients can only be made with an initial diagnostic evaluation using prolonged video electroencephalography (vEEG) at epilepsy monitoring units (EMU). The remaining 13,200 patients may benefit from surgery and appropriate assessment.

Access to Epilepsy Services for Surgery Candidacy Assessment in Ontario

As mentioned, initial diagnostic evaluation using prolonged vEEG in EMUs is the first step to begin the assessment process for surgery candidacy. However, in 2010, fewer than 750 individuals (430 adults and 309 children; 3.75% of the 20,000 people with drug-refractory epilepsy) were assessed by 1 of the 7 epilepsy centres in the province. In Ontario, there are 5 permanent pediatric EMU beds (HSC: 4; London: 1) and 13 adult EMU beds (London: 8; Toronto Western: 5), with 5 nonpermanent beds in Hamilton (2 pediatric; 2 adult) and Ottawa (1 pediatric). Even with the low referral rates for assessment, a wait time for these provincial resources remains. As identified in the field evaluation examining the use of MEG, the median wait time for vEEG is 55 days, with some patients waiting up to 441 days for assessment. At the London Health Sciences Centre, the mean wait time is 180 days for EMU assessment, with about 100 individuals currently in the cue, and at the Toronto Western Hospital, there is a mean wait time of 262 days and 90 people on the list.

Once individuals are determined to be surgical candidates, further time is spent waiting for surgical intervention. Epilepsy surgery is done at London Health Sciences Centre, HSC, and Toronto Western Hospital. In 2010, 109 epilepsy surgeries (72 adults and 37 children) were completed in the province, and invasive monitoring was used in 62 individuals (47 adults and 15 children). This case volume is only one-third of the neurosurgeons' potential annual surgical capacity. Adults waited about 4 months from the time of determining surgery candidacy to surgery at London Health Sciences Centre and Toronto Western Hospital. Most surgical interventions captured in the MEG evaluation completed at HSC occurred more than 1 year from the time of initial referral.

System-Wide Issues Related to Epilepsy Care and Surgery

The following key issues concerning epilepsy care in Ontario are limiting the overall access to health care services and contributing to delays in care, thereby significantly prolonging morbidity with reduced quality of life and increased cost to the province.

Attitudes/awareness

There is a lack of education about epilepsy surgery, and family practitioners and even neurologists know little about it. When they do know about it, the physicians are not familiar with the referral process, a problem also linked to the long wait times for assessment at the major comprehensive epilepsy centres (Toronto and London). Professional and advocacy groups can address this problem by developing and distributing standardized algorithms to educate primary care physicians about the compelling and dramatic effect epilepsy surgery can have on the lives of those adults and children who suffer from medically refractory epilepsy.

Availability of resources

There are a limited number of experienced medical specialists (neurologists with epilepsy training, epileptologists, and epilepsy neurosurgeons), electroencephalogram (EEG) technologists, neuropsychologists, psychometrists, and social workers in the field of epilepsy. This lack of personnel is due to challenges in recruiting personnel because of a lack of training programs. All epilepsy centres rely upon these specialized interprofessional teams. Furthermore, there are a limited number of EEG devices in the province, as well as magnetic resonance imaging (MRI) machines dedicated to epilepsy assessment. An additional issue is the wait for anesthesia for those adults and children who are unable to co-operate with obtaining an MRI.

Standardization

The existing equipment in the province differs by centre, limiting the ability to exchange information and increasing the number of duplicate studies. There is also a lack of standardization of MRI protocols. Furthermore, no standardized algorithm exists for the diagnosis and management of those with epilepsy, adding to significant delays in time to diagnosis and time to referral for surgery.

Geographical distribution

Since Ontario is a large province with most of the resources located in the south, there is a significant population of patients without access to any neurological care, and there are financial challenges for patients coming from the north. This problem is exacerbated by the fact that adults with epilepsy are unable to drive.

Increasing Epilepsy Surgical Capacity in the Province

Epilepsy surgery carries with it about an 80% chance of being seizure-free after surgery as well as improved quality of life and cost savings. The challenge is how to improve access to a potentially life-changing operation when less than 2% of patients with drug-refractory epilepsy currently obtain it, and for those that do, it is on average 2 decades after their first seizure. The expert panel believes the solution

lies in a 3-pronged approach. First, from an economy of scale perspective, those hospitals that currently provide epilepsy surgery could be made maximally efficient, with a longer-range view towards increasing the number of surgical centres in Ontario. The second prong would be to standardize the diagnostic and treatment care of adults and children with epilepsy to ensure that they obtain the correct diagnosis and timely referral to epilepsy centres. The third prong would be to link individuals with medically refractory epilepsy who could benefit from surgery to surgical centres by better co-ordinating their care.

Increasing capacity

Increasing capacity of existing surgical centres will require a full complement of the required professions working collaboratively, with support from the appropriate resources. The human health resources required at a surgical centre include epileptologists, neurosurgeons, neuropsychologists, psychometrists, radiologists, nurses, nurse practitioners, social workers, pharmacists, EEG technologists, as well as other professionals. These centres will likely require an increase of the amount of diagnostic infrastructure, including epilepsy monitoring unit beds, operating room resources, and preoperative imaging (e.g., MRI and MEG, among others). Increasing the capacity of current nonsurgical centres, such as the 2 centres in Hamilton (adult facility and children's hospital), would also allow them to become surgical centres.

Standardizing care

Standardizing care within Ontario will require the strategic placement of appropriate human health and diagnostic resources within the province. This could occur through the creation of "local epilepsy centres" that function according to standardized guidelines for the diagnosis, treatment, and referral to the existing epilepsy centres. These local epilepsy centres, although not providing the full spectrum of care of a surgical centre (i.e., they would have the full spectrum of diagnostic capabilities, but may not perform surgery), would interface with local physicians to identify and manage patients with epilepsy, in particular those with medically refractory epilepsy who might be surgical candidates. In addition, the local epilepsy centres would facilitate referral of potential surgical candidates to surgical centres and provide continued follow-up.

Co-ordinating care

Co-ordinating care throughout the province of Ontario will involve bringing together the local epilepsy centres with the surgical centres, and completing this cycle of care in a hub-and-spoke type of configuration. This co-ordination would require standardizing diagnostic technologies, so that information could be shared electronically among the various centres in Ontario. In addition, existing resources, in particular Telehealth, could be exploited to co-ordinate care in the far-flung northern areas of the province. These implementations would serve to increase access to epilepsy surgery for those adults and children with medically refractory epilepsy, especially for those in remote areas. Furthermore, this would reduce duplication of costly tests, while also reducing wait times for all individuals requiring diagnostic resources.

"Seizures are what we used to think about all the time. Since the successful epilepsy surgery, we just do life stuff, and it is wonderful." – Mother of a child who is now seizure-free

Epilepsy Surgery In Ontario: Increasing Access and Standardizing Care

Ontario Provincial Epilepsy Strategy Working Group – March 2011

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Appendix 3

Report of the OHTAC Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario (August 2011)

Vision Statement

Ontarians of all ages who suffer from epilepsy should have universal access to good quality, evidence-based, comprehensive health care at the right time and in the right place.

Executive Summary

As members of the Ontario Health Technology Advisory Committee (OHTAC) Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario, we are deeply grateful for the opportunity to provide our advice on how to improve access to and quality of epilepsy care in Ontario. One of the imperatives for the formation of this OHTAC expert panel has been the demonstration of inconsistent and often inadequate access to potentially curative surgical treatment of epilepsy for those adults and children in Ontario who suffer from frequent, severe, debilitating seizures that do not respond to medication. However, we did not feel it possible to create a provincial strategy for epilepsy care in Ontario that was focused only upon the surgical treatment of epilepsy. Rather, in order to provide appropriate, timely, and equal access to epilepsy surgery for those adults and children with refractory epilepsy who would benefit from this procedure, it is necessary to have in place a system that provides adequate diagnostic procedures and medical care for all Ontarians with epilepsy. This way, those who would benefit from epilepsy surgery can be identified, evaluated, and referred to regional epilepsy centres capable of providing this surgical treatment. Therefore, we have proposed a strategy to provide universal, just, equal, and timely access to quality, evidence-based, comprehensive epilepsy care across the province of Ontario.

In the report that follows we will place our work as an OHTAC expert panel in its historical context, provide background concerning what epilepsy is and what it means for those who have it, for their families, and for the society in which they live. We will document the impact of epilepsy, particularly medically refractory epilepsy (also known as drug-refractory epilepsy), in Ontario and document the critical need for health system redesign in the province in order to provide more consistent and just access to evidence-based medical and surgical care for those citizens of our province who suffer from epilepsy. We will describe the issues that people in the province with epilepsy face on a daily basis in gaining access to quality, evidence-based medical and surgical treatment of their seizures. Finally, we will provide detailed recommendations for both short-term and long-term implementation strategies regarding the provision of comprehensive, evidence-based medical and surgical care for all adults and children whose lives are burdened by epilepsy. It is important to reiterate this point: the strategy that we propose is meant to provide care for *the continuum of the life span*, from infancy to old age, because epilepsy fails to respect the boundaries of the traditional pediatric/adult medicine silos that we are all used to dealing with. Rather, this disorder strikes people of all ages and genders with a savage neutrality and relentless tenacity. We believe that the seamlessness with which our proposed strategy applies to all age groups affected by epilepsy is unique and a major strength of our recommendation.

What Led to the Formation of an OHTAC Expert Panel for a Provincial Epilepsy Strategy?

In 2007, following their review of published evidence regarding Functional Brain Imaging modalities, OHTAC recommended that a field evaluation be conducted by the PATH Research Institute at St. Joseph's Healthcare Hamilton, in collaboration with Hospital for Sick Children (HSC) in Toronto, to examine the use of magnetoencephalography (MEG) in the determination of surgical candidacy in children with medically refractory epilepsy. As part of this evaluation, the referral patterns to HSC, the surgical candidacy assessment process, and diagnostic and surgical wait times were examined. The results of this field evaluation were then presented to OHTAC in January 2011. Upon review of the study results, OHTAC requested further information regarding 3 aspects related to epilepsy care and epilepsy surgery in Ontario. These were an estimate of prevalence of medically refractory epilepsy, the identification and framing of the system-wide issues related to epilepsy care and surgery across the province, and suggestions as to how to shorten the time to diagnosis and improve access to epilepsy surgery for Ontarians with drug-refractory epilepsy. In order to respond to this OHTAC request, a Provincial Epilepsy Strategy Working Group was formed in February 2011 to provide a provincial perspective and to compile province-wide data from both pediatric and adult centres of care. The working group consisted of representatives of adult and pediatric neurology and adult and pediatric neurosurgery from all of the epilepsy centres in the province. In March 2011 the working group responded to OHTAC's request, presenting a briefing document outlining potential strategies to increase access and standardize care for people with epilepsy in Ontario. In particular, the report specifically addressed the issues related to the surgical treatment of epilepsy in Ontario. Following the presentation of the report of the Ontario Epilepsy Strategy Working Group, OHTAC commissioned an Expert Panel that consisted of members from OHTAC and from the Epilepsy Strategy Working Group, and was cochaired by the head of OHTAC and the head of the Ontario Epilepsy Strategy Working Group.

Epilepsy: What Is It and Why Is It So Terrible?

There is a reason that epilepsy has been considered a scourge throughout history. This is indeed a terrible disorder. The clinical definitions of a seizure are as follows: a sudden and abnormal paroxysmal discharge of electricity in the brain leading to an alteration in behaviour, consciousness, movement, perception, and/or sensation; the clinical definitions of epilepsy are more than one spontaneous, unprovoked seizure in anyone, be they infant, child, adolescent or adult. These definitions do not begin to convey the horror of this diagnosis. These dry clinical descriptions, while useful in diagnosis and treatment, do not convey the terror and demoralization that is imposed by the unpredictability of the seizure, and by its varying frequency and severity. Nor do these definitions denote the social stigmatization to which people with epilepsy are subjected, or illustrate the huge medical, social, and economic burden of illness that epilepsy confers on all who suffer from it. A lack of seizure control in both adults and children with epilepsy invariably and severely impacts their independence, productivity, and overall quality of life. Epilepsy leads to significant difficulties in neurodevelopment in infants and children, in behaviour and learning in school, (Drewel et al, 2008; Jones et al, 2008) in peer acceptance in adolescence, (Elliott et al, 2005) in finding employment, (Sherman, 2009) in obtaining driving privileges, which are invariably lost, in adults (Krumholz, 2009), and in cognitive decline and memory impairment (Hermann et al, 2010) and higher mortality rates (Neligan et al, 2010) in all who suffer from this disorder. The impact of epilepsy on quality of life is far greater than that of most other chronic conditions. (Wiebe et al, 1999; Kobau et al, 2008; McNelis et al, 2007)

Given these grim realities of living with epilepsy, the prevalence and incidence of epilepsy in Ontario and the status of care being provided to those with epilepsy in the province are quite sobering for anyone interested in the health and well-being of the people of Ontario, regardless of socioeconomic or cultural barriers.

What Is the Magnitude of the Problem of Epilepsy in Ontario?

Epilepsy is second only to headache amongst common neurological conditions in Ontario, but the burden of illness of epilepsy is far greater. (Tellez-Zenteno et al, 2004; Wiebe et al, 1999) The prevalence of epilepsy in Ontario (population: ~13 million) is 4 to 5 per 1,000 people. In other words, 65,000 Ontarians suffer from epilepsy: 55,000 adults and 10,000 children. About 30% of people with epilepsy have “medically refractory” epilepsy, (Kwan & Brodie, 2000) i.e., seizures that do not respond to treatment with 2 or more appropriate antiepileptic drugs. In those patients, surgery and other nonconventional treatment are required. Therefore, 20,000 Ontarians suffer from frequent disabling seizures, many on a daily basis, in spite of being on multiple antiepileptic medications. These numbers are not static. Each year 6,500 Ontarians will develop epilepsy, 1,950 of which will have refractory epilepsy. (Tellez-Zenteno et al, 2004; Wiebe et al, 1999)

What Is the Impact of Epilepsy in Ontario?

The negative impact of epilepsy is disproportionate to its prevalence. (Murray et al, 1994) People with epilepsy have lower quality of life, family function, and social support as compared to other chronically ill individuals. (Wiebe et al, 1999; Kobau et al, 2008; McNelis et al, 2007) Epilepsy is also associated with greater unmet health care needs compared to other chronic conditions (e.g., asthma, diabetes, or migraine), especially in regard to mental health care, despite having a higher health resource use overall. (Hinnell et al, 2010)

Epilepsy also results in high societal costs through loss of work productivity and high medical care expenditures. In Ontario alone, estimates of productivity loss due to disability days in the epilepsy population have been approximated by considering 250 working days per year, an average Ontarian annual income of \$25,902 (Cdn), and an average epileptic person’s 2-week disability of 1.6 days. Correcting for the fraction of working days in 2 weeks (10/14), the number of yearly disability days has been found to be 28.6 per person and 1,342,857 provincially. The corresponding yearly productivity loss is \$2,962.30 (Cdn) per individual and \$139.23 million (Cdn) for the provincial population with epilepsy. (Wiebe et al, 1999)

What Is the Impact of Medically Intractable Epilepsy in Ontario?

The 20,000 adults and children with medically refractory epilepsy in Ontario represent the largest proportion of health care expenditure in the care of epilepsy. The direct costs are associated with: frequent visits to the emergency department and life-threatening intensive care admissions, the general practitioners and/or neurologists, frequent hospital admissions (not only related to seizures, but to complications associated with seizures), the use of more than one antiepileptic drug (most patients take a combination of 2 or 3 drugs), and evaluations by nonneurologists (e.g., psychiatrists) due to comorbidities associated with epilepsy. (Canadian Institute for Health Information, 2007) The indirect costs are associated with the social costs for people who do not work, are on disability or welfare, and in those working a reduced number of work hours because of frequent seizures and/or complications associated with the seizures. Additional indirect costs relate to parents who have to stay at home with a child severely disabled from refractory epilepsy and to the special education costs accrued by such children. In these patients, epilepsy surgery may be required.

What Is the Role of Epilepsy Surgery in Medically Intractable Epilepsy?

Epilepsy surgery carries with it the hope of seizure freedom, with about an 80% chance of being seizure-free after surgery, as well as an improved quality of life and cost-savings. (Tellez-Zenteno et al, 2005; Wiebe, 2010) Certainly, not all individuals with medically refractory epilepsy will be surgical candidates,

but the majority (13,200 patients) may well benefit from surgery, while the remaining 6,800 patients would not. However, the determination of candidacy in patients with medically refractory epilepsy can only be made with proper, step-wise diagnostic evaluation, the first step being prolonged video electroencephalography (vEEG) at epilepsy monitoring units (EMUs).

What Is the Current State of Epilepsy Care in Ontario?

Currently, if a child or adult develops epilepsy, they will be seen initially either in the emergency department or by a primary care provider, i.e., family practice doctor or nurse practitioner. There is no standardized approach to diagnosis and treatment. They may or may not be treated, may or may not get basic EEG or neuroimaging, and treatment with an anticonvulsant drug may or may not be provided. If the patient fails to respond to the first drug they may or may not be referred to a neurologist. If the seizures are determined to be medically refractory, i.e., they fail to respond to 2 or more antiepileptic drugs over the course of 1 year, the patient may or may not be referred for a surgical evaluation. Again, there is no organized system of care in Ontario for patients with epilepsy, no support system for the patients and their families, and no evidence-based clinical guidelines regarding medical treatment or who should be referred for surgery. In short, given the sheer number of patients, impact on the health care system, and economic, psychosocial, and medical burden of care, epilepsy is a major public health issue in Ontario which, to date, has been inadequately addressed. Epilepsy care in Ontario varies from being nonexistent to fragmented, and access to whatever care exists is uneven and unpredictable.

What Is the Current State of Care for Medically Refractory Epilepsy in Ontario?

Considering that 20,000 people in Ontario have medically refractory epilepsy, of which a little more than 13,000 might be candidates for curative epilepsy surgery, the numbers tell a discouraging story about the issues of awareness and access in Ontario. In 2010 less than 750 individuals (3.75% of 20,000; 430 adults and 309 children) were assessed by 1 of the 7 epilepsy centres in the province. Epilepsy surgical procedures are performed at 3 of these 7 centres: London Health Sciences Centre, HSC, and Toronto Western Hospital. The critical point of entry into the epilepsy surgery diagnostic evaluation cascade is vEEG monitoring, which allows for screening of patients for epilepsy surgery (Figure 1). The vEEG monitoring of adults and children with medically refractory epilepsy to determine surgical candidacy is performed in an EMU bed. In Ontario, there are 5 permanent pediatric EMU beds (HSC 4; London 1) and 13 adult EMU beds (London 8; Toronto Western 5), with 5 nonpermanent beds in Hamilton (2 pediatric; 2 adult) and Ottawa (1 pediatric). Even with the low referral rates for assessment, there remains a wait time for these provincial EMU resources. As identified in the field evaluation examining the use of MEG in the presurgical evaluation of children with refractory epilepsy, the median wait time for vEEG in an EMU was 55 days, with some patients waiting up to 441 days for assessment. Similarly, for adults referred in 2010 the wait times are also lengthy. At London Health Sciences Centre, the mean wait time is 180 days for EMU assessment, with about 100 individuals currently in the cue, and at Toronto Western Hospital there is a mean wait time of 262 days and 90 people on the list. Individuals are determined to be surgery candidates based upon evaluation of EMU data. Once such a determination is finally made, further time is spent waiting for surgical intervention. Adults waited about 4 months from the time of surgery candidacy determination to the time of surgery at London Health Sciences Centre and Toronto Western Hospital. At HSC most surgical interventions occurred about a year after initial referral. In 2010, 109 epilepsy surgeries (72 adults and 37 children) were completed in the province, and invasive monitoring (use of intracranial electrodes to precisely localize the epileptic focus pursuant to surgical excision) was used in 62 individuals (47 adults and 15 children). This case volume is only one-third of the neurosurgeons' potential annual surgical capacity. *The bottom line is that currently in Ontario, less than 2% of the potential surgical candidates obtain surgery.*

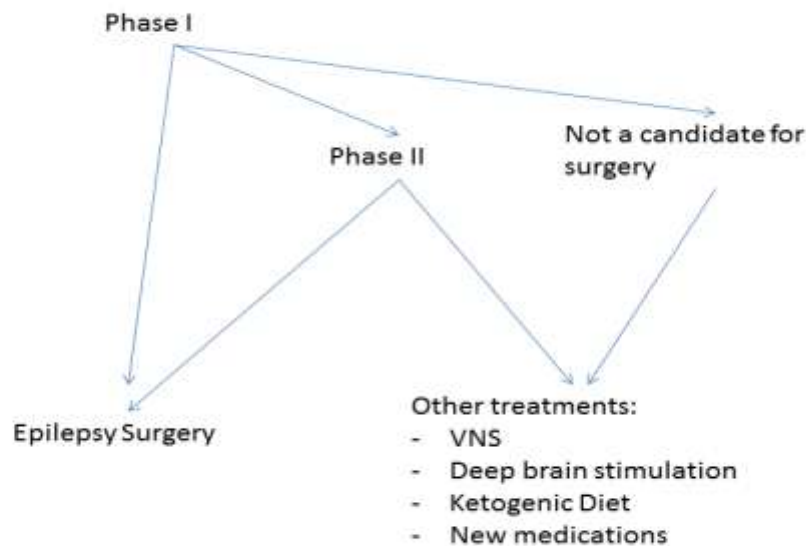


Figure 1. Pathway to Epilepsy Surgery

Abbreviation: VNS, vagus nerve stimulation.

What Are the Major Issues Concerning Epilepsy Care in Ontario?

Awareness/attitude

One of the primary issues concerning epilepsy care in the province is the lack of awareness and education about epilepsy surgery and its existence among family practitioners, and even neurologists. (Wiebe, 2010) In 2006, the International League Against Epilepsy (ILAE) highlighted that “epilepsy knowledge is deficient even amongst neurologists” and that “in the United States and Canada, more attention to primary care provider education is needed, including nurse practitioners and other similar professionals” in their report on epilepsy in North America. (Theodore et al, 2006) Despite the availability of randomized controlled trial evidence supporting epilepsy surgery, (Wiebe et al, 2001) physicians continue to prescribe medications to patients with epilepsy that could potentially be cured with epilepsy surgery and consistently underestimate the benefits and overestimate the risks associated with surgical intervention for medically refractory epilepsy. (Swartztrauber, 2004) In Sweden, for example, where published recommendations and national guidelines recommending that patients be evaluated for epilepsy surgery have existed since 1991, there is an apparent underutilization of referrals for surgical evaluation, with 58% of nonreferred patients being candidates for evaluation. (De Flon et al, 2010) Physicians caring for adults and children with epilepsy also may present erroneous information, putting epilepsy surgery in a “negative light” and, as a result, surgery may be incorrectly perceived by patients as a “last ditch effort.” (Swartztrauber et al, 2003)

Availability/organization of resources

Care for people with epilepsy should be provided by a multidisciplinary team consisting of experienced medical specialists (neurologists with epilepsy training, epileptologists and epilepsy neurosurgeons), EEG technologists, neuropsychologists, psychometrists, and social workers, all knowledgeable in the domain

of epilepsy. As with other chronic conditions, people with epilepsy require an integrated health care system that facilitates access to support for all facets of the management of their chronic illness. The need for such an integrated health care system may require changes in the existing health care delivery system. (Gruman et al, 1998) In their paper “Organizing Health Care for People With Seizures and Epilepsy,” Gruman et al provide recommendations concerning the organization of care from both a patient and provider perspective as related to the provision of care for chronic conditions. (Gruman et al, 1998) Elements of these recommendations include organizing screening and assessment processes, utilizing evidence-based clinical management, collaborative treatment planning and training, and support for patients regarding their condition, as well as proactive follow-up of patients. Further system-related issues identified were recommendations for delivery system design, decision support, and clinical information systems. (Gruman et al, 1998) Although many of these components exist in Ontario, the integration of these elements of health care across centres requires attention in order to enhance current medical and surgical care for adults and children in the province who suffer from epilepsy.

Geographical distribution

Transportation often presents significant difficulties for people with epilepsy since they cannot drive and hence have to rely on public transportation or friends and relatives to get to their health care appointments. (Swarztrauber, 2004) As Ontario is a large province with most of the resources located in the south, travelling significant distances to reach specialized health care services may be required for those people living in northern Ontario.

What Would Be the Ideal Epilepsy Care System in Ontario?

In an ideal health care system, the following would take place:

1. Anyone with new onset of spontaneous recurrent seizures would be referred by the health care provider who assessed them after the first acute event to a neurologist who could be located in a community office, a hospital clinic, or in a first seizure clinic for detailed evaluation and management. This referral to the neurologist could come from the emergency department doctors, family physicians, nurse practitioners, internists, or pediatricians. It is important to involve a neurologist from the outset in the care of an adult or child with newly diagnosed epilepsy because misdiagnosis after first seizure by family physicians is common. (Hamiwka et al, 2007) First seizure clinics in Canada have been found to be extremely effective in the treatment and triage of patients with new onset epilepsy. (Hamiwka et al, 2007) Another reason for involving a neurologist early in newly diagnosed epilepsy is that an EEG is always indicated in the initial evaluation for diagnosis, treatment, and prognostic purposes, (Krumholz et al, 2007) and interpretation of the EEG can be done only by a neurologist. Seventy percent of patients with epilepsy can be managed collaboratively (diagnosis, evaluation, and treatment) according to standard practice parameters and evidence-based guidelines.
2. The remaining 30% who failed to respond to medical treatment, the refractory group, would then be referred to a district epilepsy care centre, within reasonable geographic proximity, to initiate an epilepsy surgery work-up (Figure 1) as well as to provide psychosocial support. At the district epilepsy care centre, the patient would have access to a neurologist trained in epilepsy (epileptologist) and would receive vEEG monitoring at an EMU with technology and protocols that are standardized across the province. In this manner, the data could be easily accessed and interpreted at other district and regional epilepsy care centres in Ontario. Similarly, a brain magnetic resonance imaging (MRI) could be performed at the district epilepsy care centre using 3 Tesla MRI scanning protocols, also standardized across the province. Furthermore, standardized neuropsychological testing and evaluation could be performed by trained neuropsychologists, psychometrists, and social workers on hand at each district epilepsy care centre. The results of

this extensive evaluation, with recommendations for further treatment, would be sent back to the referring physician for implementation.

3. If, after undergoing this evaluation, the patient was deemed to be a surgical candidate, a referral would be made from the district epilepsy care centre to the regional epilepsy care centre for final evaluation and, if indicated, epilepsy surgery. Since all EMU, MRI, and neuropsychological protocols would be standardized across the province, the data could be utilized at any district or regional epilepsy care centre in Ontario. The regional epilepsy care centre would have positron emission tomography (PET) (Carne et al, 2004; Chugani et al, 2011) and MEG (Stefan et al, 2011) facilities available to further evaluate surgical candidacy, as well the ability to carry out intracranial monitoring (brain mapping) and to perform the epilepsy surgery if indicated. (For a detailed description of the presurgical evaluation, see Go and Snead, 2008) In addition, each regional epilepsy care centre would have EMUs, 3 Tesla MRI, neuropsychology, and social work capability to care for those epilepsy patients referred from within their respective catchment areas for surgical evaluation.

Recommendations for a Provincial Strategy for Epilepsy Care in Ontario

Short Term

Maximize current system capacity:

- The Ministry of Health and Long Term Care should support the infrastructure in already existing regional epilepsy centres with the ability to perform epilepsy surgery (i.e., London Health Sciences Centre, Toronto Western Hospital, and HSC), and district epilepsy centres that can do initial EMU, MRI, and neuropsychological evaluations (i.e., London Children's Hospital, McMaster Children's Hospital, Hamilton Health Sciences Centre, and Children's Hospital of Eastern Ontario). Existing infrastructure should be increased not only to support the current capacity, but to maximize capacity. For example, in London, the EMU loses 1 to 2 beds daily to off-service patients. The first step would be that the government carry out a gap analysis of the regional epilepsy centres (London and Toronto) and the currently existing district centres (London Children's Hospital, Ottawa, and Hamilton) to determine what their current and maximal capacity for the evaluation of surgical candidacy is for adults and children with medically refractory epilepsy.
- Once the requirements for maximizing capacity are defined in terms of capital equipment, e.g., 3 Tesla MRI, MEG, vEEG, beds (dedicated EMU beds), operating room time, and human resources (EEG technologists, neuropsychologists, social workers), the Ministry should provide the resources to meet these requirements.
- Standardization of protocols for EMUs and MRI scanning for all medically refractory epilepsy patients across the province who are undergoing diagnostic evaluation for epilepsy surgery should be mandated by the Ministry
- The Ministry should establish independent budgets for each centre based on the volumes of patients and surgeries. It should be noted that the budgets for all district and regional epilepsy care centers come from their respective local health integration network (LHIN). Therefore, patients referred from outside the LHIN, which is a frequent occurrence, will cause losses to the hospital's budget. For example, in London 60% of the medically refractory epilepsy population comes from outside the LHIN.

Longer Term

- The government should establish new district and regional epilepsy centres. McMaster Children's Hospital and Hamilton General Hospital are close to being regional epilepsy centres for pediatric and adult epilepsy surgery, respectively. They should receive the resources to reach this goal, an excellent example of maximizing existing resources, since the gap is minimal. Similarly, the government should provide the needed resources to make London Children's Hospital into a regional epilepsy care centre. The required resources would be determined by the government-sponsored gap analysis.
- A new district epilepsy centre is proposed for northern Ontario. Ideally, this centre should be affiliated with the northern medical schools and be supplied with EMU and neurophysiology resources appropriate for their service catchment area as determined by the Ontario Ministry of Health and Long-term Care, e.g., Sudbury or Thunder Bay.
- Standardization of care and development of guidelines:
 - The government should create standardized management plans for epilepsy in adults and children across the province, starting with the primary care providers.
 - The government should provide a standardized approach for those adults and children with medically refractory epilepsy who are not candidates for surgery. This represents almost 7,000 people in Ontario. Alternative beneficial therapies for this group of patients are vagal nerve stimulation, available at all regional epilepsy care centres, and dietary therapies, available at district epilepsy care centres. (See Figure 1 for pathway to epilepsy surgery and alternative therapies for those who are not surgical candidates.)
 - The government should establish a provincial guideline for epilepsy surgery referrals.
 - The government should create a standardized process for transitional care between pediatric and adult programs. Such a process is critical for a Provincial Strategy for Epilepsy Care to work since seizures often have their onset in infancy and childhood, yet continue throughout life. In order to maximize the care of someone with life-long epilepsy, it is necessary to insure transitional care from adolescence into adulthood.
- Training:
 - The government should establish provincially funded training programs for epileptologists, epilepsy surgeons, dieticians for the ketogenic diet program, and EEG technologists, in partnership with regional epilepsy centres.
 - The government should train more neuropsychologists and social workers with expertise in epilepsy.
 - The government should increase nonspecialist psychology services in the north or smaller population centres to do front-line work with children and adults with epilepsy.
 - Education about the compelling and dramatic effect epilepsy surgery can have on the lives of those adults and children who suffer from medically refractory epilepsy should be provided to primary care practitioners, pediatricians, internists, and neurologists through professional organizations and advocacy groups.
- Outreach and provision of epilepsy care in northern Ontario:
 - The government should support assessments that can be done via telemedicine, an extremely efficient modality of treatment and physician patient interaction. (Ahmed et al, 2010)
 - The government should organize coaching teams to help primary care providers care for epilepsy patients and make appropriate referrals to district epilepsy care centres.

- The government should establish a provincial wait time strategy for EMU admissions, MRI for epilepsy work-up, diet initiation, and epilepsy surgery.
- The government should establish and maintain a provincial epilepsy database.
- The government should create a permanent provincial epilepsy expert advisory panel to establish and evaluate benchmarks for the Ontario Epilepsy Program. The epilepsy community (e.g., Neurological Health Charities of Ontario and local epilepsy advocacy groups) should have a role on this panel, as should an ethicist, to address wait time issues and those of consent and assent for epilepsy surgery. (Ibrahim et al, 2011) This advisory panel should develop strategies to eliminate barriers to access related to socio-economic status and diverse cultures, and also examine the impact of continued seizure activity on quality of life or cognitive function during wait time, and determine how best to factor these issues into the prioritization process.

Conclusion: The Opportunity

The fact that OHTAC has taken the initiative to examine epilepsy care in Ontario in detail, with a particular focus on access to potentially curative epilepsy surgery, presents a huge opportunity for Ontario to put into place a comprehensive, evidence-based system of care for all those adults and children in the province who suffer from epilepsy. In creating such a system, Ontario has the opportunity to set the gold standard for comprehensive, evidence-based medical and surgical epilepsy care worldwide.

Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario

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