










## Brief Communication

# Evaluating the Current State of Epilepsy Care in the Province of Ontario

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**ABSTRACT:** There are numerous challenges pertaining to epilepsy care across Ontario, including Epilepsy Monitoring Unit (EMU) bed pressures, surgical access and community supports. We sampled the current clinical, community and operational state of Ontario epilepsy centres and community epilepsy agencies post COVID-19 pandemic. A 44-item survey was distributed to all 11 district and regional adult and paediatric Ontario epilepsy centres. Qualitative responses were collected from community epilepsy agencies. Results revealed ongoing gaps in epilepsy care across Ontario, with EMU bed pressures and labour shortages being limiting factors. A clinical network advising the Ontario Ministry of Health will improve access to epilepsy care.

**RÉSUMÉ :** Évaluer l'état actuel des soins destinés à l'épilepsie dans la province de l'Ontario. Les soins de l'épilepsie offerts en Ontario font face à de nombreux défis liés notamment à la pression sur les lits des services d'urgence, à l'accès aux chirurgies et aux soutiens offerts au sein des communautés. Nous avons donc cherché à étudier l'état clinique, communautaire et opérationnel actuel des centres de soins et des agences communautaires de l'épilepsie de l'Ontario à la suite de la pandémie de COVID-19. Ainsi, un sondage comportant 44 questions a été distribué aux 11 centres d'épilepsie adultes et pédiatriques des régions et districts de cette province. Des réponses de nature qualitative ont été par ailleurs recueillies auprès des agences communautaires de l'épilepsie. Nos résultats ont révélé des lacunes persistantes dans les soins destinés à cette maladie, la pression sur les lits des services d'urgence, de même que la pénurie de main-d'œuvre, étant des facteurs limitants. Enfin, un réseau clinique conseillant le ministère de la Santé de l'Ontario améliorera l'accès aux soins de l'épilepsie.

**Keywords:** epilepsy; epilepsy surgery

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Epilepsy is a highly prevalent neurological condition which is estimated to affect approximately 95 000 individuals across Ontario.<sup>1</sup> Given the stigma associated with the disclosure of an epilepsy diagnosis, this is likely underestimated. Individuals with epilepsy have reduced health-related quality of life, secondary not only to the direct impact of seizures, but also the adverse

effects from anti-seizure medications as well as psychological co-morbidities.<sup>2</sup>

Approximately 30% of those with epilepsy will be medically-refractory. Epilepsy surgery is an evidence-based, effective intervention for medically-refractory epilepsy, resulting in seizure freedom in up to 80% of patients in addition to improvement in

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psychosocial co-morbidities and quality of life.<sup>3</sup> Epilepsy surgery has also been shown to reduce long-term healthcare utilisation when compared to epilepsies treated medically.<sup>4</sup> Despite this, epilepsy surgery remains an under-utilized resource with only 2% of eligible patients being referred for pre-surgical work-up, and 1% receiving surgery.<sup>5</sup> Possible explanations include long wait lists for Epilepsy Monitoring Units (EMUs) as well as low referral rates.<sup>6</sup>

To address these challenges, all existing provincial epilepsy-related programmes, resources and stakeholders have been unified into a clinical and community network, designated OPEN (Ontario Provincial Epilepsy Network). To optimise planning, access and resource allocation we sampled the current clinical, community and operational state of Ontario epilepsy centres and community epilepsy agencies post COVID-19 pandemic.

A 44-item survey was distributed to the site leads at all 11 district (defined as having an EMU and capability to perform phase I pre-surgical evaluation) and regional (defined as performing both phases I and II evaluation, as well as surgical treatment) adult and paediatric epilepsy centres across Ontario. The survey included six sections: Site Location, Human Resources, Clinic Operations, EMU Logistics, Presurgical Evaluation and Epilepsy Surgery. Questions were designed to gain a better understanding of staff resources, available services and wait times for pre-surgical evaluation/surgery. Qualitative responses were collected from 13 community epilepsy agencies as well as Epilepsy Ontario post-survey regarding gaps in care. These community-based organisations work to provide public education and awareness regarding epilepsy, as well as to provide programmes and services for individuals with epilepsy and their families. The results from our survey are outlined below.

### Site location

Responses were recorded from all 11 sites (7 district, 4 regional). Ten centres reported plans for expansion of services, including EEG technologist hiring (55%), epilepsy specialist hiring (45%), registered nurse hiring (36%), EMU bed expansion (27%) and offering epilepsy surgery (27%).

### Human resources

Centres reported a range of 1–11 epilepsy specialists (median = 3), 0–3 epilepsy neurosurgeons (median = 1, nearly all working in regional surgical centres), and 2–11 EEG technologists (median = 6, all of whom participate in all EEG laboratory services including EMU, ambulatory, routine and continuous EEGs). Forty-five percent of centres indicated having separate staff to act as EMU coordinators. Sixty-four percent of centres have epilepsy fellows, of which 71% reported having 1–2 fellows and 2 centres reported having more than 3 fellows. All centres indicated being affected by labour shortages, most notably EEG technologists, nursing staff and epilepsy specialists.

### Clinic operations

Thirty-six percent of centres reported having 0 clinic nurses, whereas no centres reported having greater than 3 nurses. Forty-five percent indicated having a nurse practitioner as a part of their epilepsy group or clinical staff. A further 45% cited wait times of 1–3 months for clinic referrals triaged as urgent, and 73% cited 6–12 months for non-urgent referrals, with 1 centre reporting wait times of greater than 24 months. VNS programming was reported to be available at 91% of centres, although only 27% offer DBS

programming. A Ketogenic Diet Program is available at 73% of centres. Seventy-three percent of centres indicated having an adolescent transition programme, however, the minimum wait time cited was 3–6 months (45%), with one centre citing wait times of greater than 24 months for adolescents waiting to see an adult specialist. Additional subspecialty clinics are offered at certain centres include first seizure clinics (55%), epilepsy genetics clinics (36%), tuberous sclerosis complex clinics (27%) and women's health clinics (18%).

### EMU logistics

Fifty percent of centres cited EMU wait times of 1–3 months for urgent surgical and 50% cited 6–24 months for non-urgent surgical referrals. For non-surgical referrals, 50% of centres reported wait times of 6–24 months for non-urgent referrals. The number of total EMU beds ranged from 0 to 11 (0–10 operational), with 64% of centres citing between 2 and 4 discharges per week. Thirty-six percent of centres indicated their EMU is not open on weekends, and only 3 centres indicated EMU beds are reliably protected during surge times.

### Pre-surgical evaluation

If not otherwise limited by various constraints, 10 centres indicated having the infrastructure to perform additional pre-surgical tests beyond what is currently offered, including 1.5T MRI, fMRI, PET and SPECT.

### Epilepsy surgery

The surgeries most frequently performed included VNS implantations, lobectomies and lesionectomies, sEEG, callosotomies and DBS. Wait times for sEEG ranged from less than 3–24 months, while 6/11 (55%) of centres reported wait times of 6 months or less for temporal lobe resection. Wait times for VNS implantation, DBS and callosotomy varied across centres, ranging from less than 3 months–12 months for VNS/DBS and 24 months for callosotomy. Only 2/11 (18%) of centres offered laser interstitial thermal therapy. The wait time from EMU data capture to surgical conference presentation was less than 3 months at 63% of centres, and whereas district centres reported variable wait times for conferences outside their own centre, ranging from less than 3 to greater than 24 months.

### Community agencies

Responses were recorded from 13 community health agencies and Epilepsy Ontario. Epilepsy Ontario reported a need for additional system navigators, and community health agencies identified need for counsellors, social workers and educators.

Overall, the results of our survey reveal ongoing gaps in epilepsy care across Ontario post COVID-19 pandemic, particularly pertaining to access and delivery of care for patients with medically-refractory epilepsy. Limiting factors include EMU bed pressures and labour shortages, identified globally, including epileptologists, though the median of 3 specialists per centre is in line with previous studies from the U.S.<sup>7</sup> Although significant variability exists across centres, wait times for surgical admissions are quite variable, anywhere between 3 and 24 months, although no standardised definition of "urgent" was used by responding centres. Another limitation was possible response bias as the waiting times were derived from respondents' knowledge of their institutional workflows and the responses provided may have been

perceived as “more acceptable” than the “real world” waiting times. Further, the majority of centres indicated EMU beds are not protected during surge times. Labour shortages are a pervasive issue across all epilepsy centres and community agencies, with shortages of EEG technologists, nursing staff and epileptologists being the most frequently cited. Inclusion and integration of patient care pathways with community health partners are also needed.

A 2015 survey of Canadian neurologists reported an average wait time for epilepsy surgical evaluation of 8.6 months, with the longest wait times reported in Saskatchewan (14.2 months) and British Columbia (10.2 months), and the shortest wait times reported in Quebec (5.9 months) and Alberta (7.9 months).<sup>8</sup> A further pre-COVID study from Saskatchewan revealed time from initial epilepsy consult to video EEG was 7 months, and time from consultation to surgery was 17 months.<sup>9</sup> In Ontario, a 2012 report indicated EMU wait times to be an average of 180 days and 262 days at two respective regional epilepsy centres.<sup>6</sup> Unfortunately, no guideline or benchmark on acceptable waiting time exists currently. There is no Canadian data regarding pre-surgical evaluation wait times post-pandemic. Our results suggest that current Ontario wait times remain prolonged, although may be minimally shorter than these pre-pandemic Canadian reports, particularly for surgical cases triaged as urgent. This is likely related to reduced surgical caseloads. There is evidence that reduced surgical wait times are associated with improved seizure control post-operatively,<sup>10</sup> suggesting that improving surgical access and availability would be an important priority for the province.

Clinical networks integrate clinicians and consumers to identify and address systems-based healthcare problems in order to improve delivery of care. OPEN has been established based on operating models of existing clinical networks within and outside of Ontario, including but not limited to agencies operating under Ontario Health such as Cancer Care Ontario and Critical Care Services Ontario, as well as various strategic clinical networks operating under Alberta Health Services.

A priority of OPEN includes evaluating wait times and capacity across Ontario Epilepsy networks, as well as collecting bottom-up priorities from stakeholders. Our survey has identified areas of need from all provincial epilepsy centres and community agencies. A clinical network serving in an advisory capacity to the Ministry of Health will serve as a logical next step to allow for effective prioritisation of resource distribution and ultimately improve access to epilepsy care.

**Author contributions.** CV: interpreted data, drafting and revising manuscript. TF: designed/conceptualized study, revising manuscript. AA/DA/JB/SdR/ED/AH/GI/KJ/LL/KM/MN/NP/RR/PR/JR/MS/DS/DS/TV/SW/RW/IY: revising manuscript.

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grant recipient; Hydrocephalous Canada Medical Advisory Board member; ED: Jazz Pharmaceuticals, UCB Pharma, Takeda consulting; Jazz Pharmaceuticals educational payments; Neurocrine Advisory Board member; GI: LinaNova grant recipient; LinaNova, Medtronic, Synergia consulting/educational payments/conference support/Advisory Board member; KJ: New Investigator Fund Grant Hamilton Health Sciences grant recipient; ECHO Epilepsy across the lifespan educational payment; Ontario Epilepsy Genetics Testing Program Committee member; LL: CFI grant recipient; UCD, Paladin, Jazz Pharmaceuticals consulting; speaker honoraria for Paladin, UCB, Eisai, Sunovion; CADTH Advisory Board member; KM: ECHO Epilepsy across the lifetime course facilitator; Ontario TSC Network Executive member; site principal investigator Epygenix sponsored ARGUS trial; DS: Speaker honorarium UCB Canada; CMPA expert medicolegal opinion; financial support for meetings from International Epilepsy Surgery Society; Canadian Neuro secretary/treasurer; DSw: received support from Epilepsy Ontario for manuscript content; Community Services Recovery Fund, Red Cross grant recipient; Consulting for Epilepsy Ontario, Durham Community Foundation, Theatre 3x60 (Theatre on the Ridge), Georgian Bay Symphony; Durham Community Foundation educational conference payments; holds US technology stock holdings; immediate family member with undiagnosed seizures; SW: CIHR transition in epilepsy grant recipient; ECHO Epilepsy across the lifetime educational payment; Ontario Brain Institute Advisory Board Member; RW: Jazz Pharmaceuticals consulting.

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