



## Commentary

# Disparities In Drug-Resistant Epilepsy Care In Canada

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**Keywords:** Barriers; epilepsy; epilepsy surgery; inequities

In a review of the surgical management of epilepsy published in 2014 by CMAJ, Jette et al. suggested that a better understanding of the barriers to epilepsy surgery is needed to increase the low rates of epilepsy surgery for the treatment of drug-resistant epilepsy (DRE).<sup>1</sup> We discuss these barriers, provide an update on the disparities in DRE care across Canada and discuss strategies that could be used to address them.

Epilepsy is one of the most common neurological conditions worldwide and accounts for a significant proportion of the global disease burden. In Canada, epilepsy prevalence is estimated at 5 to 6 per 1,000 people.<sup>2</sup> Epilepsy often significantly and negatively affects many aspects of patients' lives and increases mortality risk.

Patients newly diagnosed with epilepsy are treated with anti-seizure medications (ASMs), but approximately one-third have DRE.<sup>2</sup> Fortunately, epilepsy surgery is a safe and effective treatment for appropriately chosen patients.<sup>1</sup> Patients are typically eligible for assessment for epilepsy surgery candidacy if their seizures are disabling and resistant to ASMs.<sup>1</sup> Patients are assessed for epilepsy surgery candidacy as inpatients in an Epilepsy Monitoring Unit (EMU) using a series of investigations: prolonged video-electroencephalogram (vEEG) monitoring, magnetic resonance imaging (MRI), neuropsychological assessments, and in some cases, functional neuroimaging (positron emission tomography [PET], single photon emission computed tomography [SPECT]) and intracranial EEG.

However, not all patients assessed are eligible to receive epilepsy surgery. Contraindications include an unidentifiable seizure focus and severe active psychiatric conditions.<sup>1</sup> Ineligible patients are considered for alternative therapies, such as vagus nerve and deep brain stimulation. Unless alternatives to ASMs are tried, patients with DRE typically continue experiencing seizures and their associated adverse effects.<sup>1</sup> Therefore, it is recommended that patients are referred for assessment for epilepsy surgery candidacy when DRE is diagnosed.

However, many patients in Canada are not considered for epilepsy surgery promptly following their diagnosis of DRE. In a survey of 327 Canadian neurologists treating people with epilepsy, over 75% identified inadequate healthcare resources, including long wait times (34.4%), limited resources (13.7%), access (11.3%) and distance (7.0%), as the most important barrier to epilepsy surgery.<sup>3</sup> This finding indicates that inadequate healthcare

resources is likely the most significant barrier to the effective management of DRE in Canada.

## What resources are currently available to treat DRE in Canada?

The resources needed to assess patients for epilepsy surgery candidacy are available in Canada but insufficient to treat all who may benefit. Additionally, given the considerable geographic spread of the population, some Canadians with DRE experience more significant healthcare-related barriers than others. Neurologists and epileptologists are essential resources for managing DRE effectively. In 2018, there were 2.8 neurologists per 100,000 Canadian residents.<sup>4</sup> However, that figure varied between the provinces and territories, with no neurologists in any of the three territories and 3.6 neurologists per 100,000 people in Quebec.<sup>4</sup> The number of epileptologists in Canada is only a small proportion of all neurologists. Therefore, there is likely an insufficient number available to treat all Canadian residents with DRE, and those available are unlikely to be equally distributed.

The precise number of EEG machines in Canada is also unknown. However, the availability of imaging machines used for DRE treatment is approximately known. A 2017 inventory identified 366 MRI scanners, 330 SPECT scanners, 51 PET-CT, and 3 PET-MRI machines.<sup>5</sup> Most imaging resources were in urban settings, with the greatest number and variety in Ontario, Quebec, Alberta and British Columbia.

To our knowledge, EMU beds in Canada have not been previously enumerated. Therefore, we contacted personnel from each EMU across the country to determine the number of EMU beds available within each province and territory relative to its estimated prevalence of DRE (Table 1). Seven of the 13 provinces and territories do not have any EMU beds, including all three territories. Among the six provinces with at least one bed, the number per 1,000 people with refractory epilepsy ranges from 0.83 in British Columbia to 2.5 in Nova Scotia. These figures indicate that there is a disparity between the provinces and territories in the availability of EMU beds, and there is an insufficient number of beds within the provinces with at least one. Since assessment for epilepsy surgery candidacy must occur in an EMU, the insufficient number of EMU beds is a significant barrier to treating patients with DRE.

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**Cite this article:** Couper RG, Antaya T, Nguyen DK, and Burneo JG. Disparities In Drug-Resistant Epilepsy Care In Canada. *The Canadian Journal of Neurological Sciences*, <https://doi.org/10.1017/cjn.2024.57>

**Table 1.** Estimates of the number of epilepsy monitoring unit (EMU) beds relative to the estimated number of people with refractory epilepsy in each province and territory in Canada

Province/Territory	Population <sup>a</sup>	Prevalence of epilepsy per 1,000 people <sup>2</sup>	Expected number of PWE <sup>b</sup>	Expected number of people with DRE <sup>c</sup>	Number of EMU beds	Number of beds per 1,000 with DRE <sup>d</sup>
British Columbia	5,581,127	5.2	29,022	9,674	8 total (4 adult, 4 pediatric)	0.83
Alberta	4,756,408	5.7	27,112	9,037	10 total (8 adult, 2 pediatric)	1.11
Saskatchewan	1,218,976	5.2	6,339	2,113	None	0
Manitoba	1,465,440	4.4	6,448	2,149	3 total (2 adult, 1 pediatric)	1.40
Ontario	15,801,768	5.2	82,169	27,390	41 total (28 adult, 13 pediatric)	1.50
Quebec	8,948,540	5.4	48,322	16,107	19 total (14 adult, 5 pediatric)	1.18
New Brunswick	842,725	6.9	5,815	1,938	None	0
Nova Scotia	1,066,416	6.7	7,145	2,382	6 total (4 adult, 2 pediatric)	2.52
Prince Edward Island	175,853	4.4	774	258	None	0
Newfoundland & Labrador	540,418	6.8	3,675	1,225	None	0
Nunavut	40,817	3.7	152	51	None	0
Northwest Territories	44,760	3.7	166	56	None	0
Yukon	45,148	3.7	168	56	None	0

DRE = drug-resistant epilepsy; PWE = people with epilepsy.

<sup>a</sup>Population of provinces according to Statistics Canada Q4 2023 (<https://doi.org/10.25318/1710000901-eng>).

<sup>b</sup>Expected number of PWE calculated by multiplying population by prevalence.

<sup>c</sup>Expected number of people with DRE calculated by dividing total expected number by 3.

<sup>d</sup>Number of beds per 1,000 with DRE calculated by dividing the number of beds by DRE.

### What strategies could reduce disparities in DRE care within and between provinces and territories?

There are no national strategies to increase the rates of epilepsy surgery assessment and receipt. However, the Ontario Ministry of Health and Long-Term Care established a strategy in 2013 to improve the care of epilepsy within the province. This strategy was multifaceted but included increasing the number of EMU beds available and creating the Epilepsy Implementation Task Force (EITF). The EITF was tasked with implementing the strategy by coordinating resources and waitlists and establishing protocols to standardize care across centers, among other methods. One of the main accomplishments of the EITF thus far is the creation of a set of Provincial Guidelines on a range of epilepsy care-related topics, including the appropriate management of DRE and a description of the referral pathways to EMUs for assessment for epilepsy surgery candidacy.

Programs like Project ECHO: Epilepsy Across the Lifespan could also be implemented nationally to address these disparities. This program currently connects community healthcare providers in Ontario to provincial Comprehensive Epilepsy Programs, comprising multidisciplinary epilepsy care teams of epileptologists, neuropsychologists and nurse practitioners, among others, to optimize their treatment of patients with epilepsy through case-based education.

The availability and accessibility of resources to treat DRE in Canada remain limited and unequally distributed between regions.

Increasing resources allocated to epilepsy care in all provinces and territories and implementing strategies such as those used in Ontario are urgently needed to improve DRE care in Canada.

**Author contributions.** GC, TA, DKN and JB wrote the commentary. All authors commented and edited the final version.

**Funding statement.** None.

**Competing interests.** GC and TA report no conflicts of interest. DKN reports honoraria from Paladin Labs, Pendopharm, UCB Canada and Eisai and has participated on boards for Paladin Labs. JB holds the Jack Cowin Endowed Chair in Epilepsy Research at Western University.

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