

The Institute of Medicine of the United States (US) National Academies has recently released a document entitled: "Epilepsy across the spectrum: Promoting health and understanding"<sup>1</sup>. In this document, the Committee on the Public Health Dimensions of the Epilepsies has stated that epilepsy is a common and complex neurological disorder. The committee has emphasized that epilepsy affects the health and quality of life of those individuals with the disorder, and that there is a need for a holistic approach to enhance the care of patients with epilepsy. In addition, they pointed out that there is a need to improve and coordinate health and human services, as well as timely referrals and facilitate access to treatment. Furthermore, it was stressed that there is a need to improve education for patients, families, and physicians, and a need to eliminate the stigma of epilepsy. Even though the Canadian health system differs from the one South of the border, the findings of the current situation of epilepsy care in the US, described in this 409-page report are analogous to our current situation, and necessitate discussion with government, professional, and lay organizations in Canada.

Going forward, there is a need to develop and evaluate prevention efforts for epilepsy and its consequences. The landscape of epilepsy is constantly changing and involves very diverse segments of the Canadian population. For example, in the elderly, stroke remains the main cause of epilepsy, and the effect of seizures in health-resource utilization, as well as medical outcome of patients affected by stroke is worse than those without seizures<sup>2</sup>. As another example, traumatic brain injury is a common cause of epilepsy that affects Canadians. Many Canadian soldiers returning from Afghanistan who have suffered blast injuries will be susceptible to developing epilepsy<sup>3</sup>. Finally, the incidence of neurocysticercosis (NCC), the most common cause of focal epilepsy in the developing part of the world, is rising in the US. Although it is not a major health issue in Canada at this time, sporadic cases being reported, usually in individuals immigrating from or who have traveled in endemic areas.<sup>4</sup> Given the dynamic and diverse nature of the Canadian population, reporting and surveillance of future cases of NCC in Canada is needed.

Improving the early identification of epilepsy and its comorbid health conditions is the most important issue affecting Canadians with epilepsy. It is well known that approximately 30% of patients with epilepsy will become intractable.<sup>5</sup> Even though they may represent a small proportion of individuals, the health expenditure is much higher in this group than in the one with controlled epilepsy. A recent report from Ontario revealed that only 2% of patients with intractable epilepsy receive adequate treatment, which consists of a referral to a comprehensive epilepsy program<sup>6</sup>. The situation is most likely worse elsewhere, given the fact that not all regions of Canada have comprehensive epilepsy programs. Furthermore, the small percentage of patients referred to comprehensive programs wait for long periods of time before they are seen by a specialist and assessed in epilepsy monitoring units. Hence, efforts like the

recent Epilepsy Network for a Provincial Strategy in Ontario are needed across the country, and require support by political authorities<sup>6</sup>. Efforts should be concentrated in supporting the existing epilepsy programs with independent funding, and in the development of smaller epilepsy districts to decrease the burden suffered by the comprehensive programs, as not all patients with intractable epilepsy are surgical candidates.

The lack of knowledge about intractable epilepsy and the existence of different surgical procedures to treat the epilepsies are reflected by the fact that the majority of the patients referred to comprehensive epilepsy programs are over a decade after the onset of their seizures. Even though the only randomized-controlled trial comparing surgery versus medications in patients with epilepsy difficult-to-control was performed in Canada<sup>7</sup>, and that Canadians were among those who pioneered the surgical treatment of the epilepsies, knowledge of the surgical options for epilepsy is not widespread in the general medical community.

It is also important to improve and expand education among patients and families, and at the same time inform the media, increasing awareness and consequently eliminate stigma. Stigma has a detrimental effect on those with epilepsy and their families, preventing them from contributing fully to society. Despite the fractionated existence of the lay organizations, their participation is vital. A strong national organization linking small community groups is needed. Although there are national lay organizations for Epilepsy, there is no consistent formal link between these organizations, the Provincial organizations and, the local organizations that serve patients with epilepsy.

In a time where brain-related research is increasing and new discoveries are made, the current situation of the economy does not allow for increased funding. Even though epilepsy research is underfunded<sup>8</sup>, the situation is not improving, despite Canadian Institutes of Health Research's efforts to outline a clear health research roadmap with four key priorities arch<sup>9</sup>. Private funding is needed. However given the fact that patients with epilepsy are often not part of the workforce and thus do not have a strong voice in Canadian society, funding is extremely limited. On the contrary, much less prevalent neurological diseases like Parkinson's Disease or multiple sclerosis have better funding mechanisms, and are strongly supported by private organizations. Multicentre, collaborative, nationally-based research is needed, and the standardization of research protocols is needed. In spite of these funding challenges, Canada continues to be a leader in Epilepsy Research, as the research publications per capita exceeds any other country.

Organizations like the Pan American Health Organization (PAHO), the World Health Organization, the International League Against Epilepsy, and the International Bureau of Epilepsy have started different campaigns to raise awareness of epilepsy among health professionals and the public in general. These organizations have identified service gaps and have done demonstration projects in certain developing countries, promoting the involvement of government and public health

departments. PAHO in particular, has initiated a "Regional Strategy and Plan of Action on Epilepsy", which the Government of Canada has endorsed, but has yet to act on its recommendations.

Finally, we believe that the starting point should be the establishment of independent provincial and federal funding for epilepsy care, similar to what exists for stroke care in some Provinces, and that epilepsy research should be given priority by granting agencies.

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