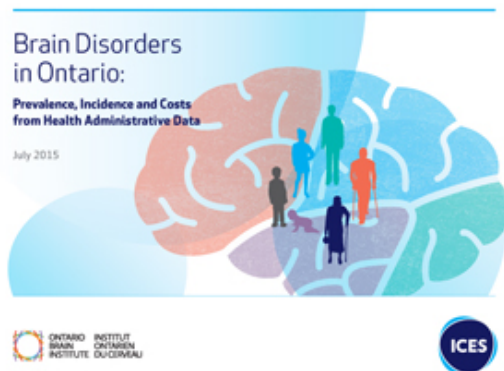


# Impact of Epilepsy in Ontario: New report on brain disorders released

July 9, 2015 - The Ontario Brain Institute (OBI) in collaboration with the Institute for Clinical and Evaluative Sciences (ICES) released a report this week that provides new Ontario-specific findings for thirteen brain disorders, including epilepsy.

The neurological conditions described in the report include those that begin early in life, such as spina bifida and cerebral palsy, those that begin in adults, such as dementia and parkinsonism, and disorders that can begin at any age, such as epilepsy.



Read the full report online:

<http://www.ices.on.ca/flip-publication/BrainDisordersInOntario2015/index.html>

Ng R, Maxwell CJ, Yates EA, Nysten K, Antflick J, Jetté N, Bronskill SE. Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data. Toronto, ON: Institute for Clinical Evaluative Sciences; 2015

## Data gathering:

- The 15-year cumulative prevalence of epilepsy in Ontario from 1995-2010 is reported. A demographic profile (as of April 1, 2010) of the individuals identified with epilepsy as well as the public costs for one year of health system use (2010/11) are also reported.
- Health administrative records from 12 linked provincial databases were the source of the data. This includes records of physician claims, hospital discharges and emergency department visits as well as publicly funded drug benefits, home care and long-term care. Electronic medical records (EMRs) were not part of this study.
- The case selection method for epilepsy has been previously validated for Ontario data and found to be sensitive and highly specific, 73.7 and 99.8, respectively. The detection algorithm for epilepsy was classified as evidence grade 1 (highest level). It is extremely important to have a good case definition when doing epidemiological research with administrative records to ensure high quality data.

## Incidence, prevalence and demographics:

- **89,867 Ontarians with epilepsy** were identified from health administrative data over the 15 year study period (1995 to 2010).
- Between 2004/05 and 2010/11 there was **no overall change in the annual rate of new cases** of epilepsy. However, the number of individuals with newly diagnosed epilepsy per year grew from 5,510 (2004/05) to 5,981 (2010/11) which correlated with the growth of the Ontario population.

- **Epilepsy affects people of all ages** from infants to seniors with roughly equal distribution in both males (51%) and females (49%). There were nearly 90,000 people identified with epilepsy over the 15 year period. In 2010 the age demographics of this group were as follows: 16% were children (0-17 years), 69% were adults (18-64 years) and 15% were older adults (65 years and older). This breakdown by age provides new data that is especially important for program planning and for predicting potential service needs of people with epilepsy.
- The 15-year **cumulative prevalence of epilepsy was lower in children (5.3 per 1000) than adults (7.2 per 1000)**.
- There was **no difference** in the prevalence of epilepsy **between younger adults (18-64 years) and seniors (65 years and older)**. Both age groups had a cumulative prevalence of 7.2 per 1000.
- A **higher percentage of people identified with epilepsy lived in neighbourhoods with the lowest household incomes (23.6%)** compared to those who lived in neighbourhoods with the highest incomes (17.3%). Schizophrenia was the only condition with greater disparity in socioeconomic status than epilepsy. Among the ten other brain disorders in the report some were also skewed towards a higher percentage of people in the neighbourhoods with the lowest household incomes, while some of the conditions had prevalent populations that were evenly distributed across all five neighbourhood income quintiles and some were skewed in the opposite direction with slightly higher percentages of people in the neighbourhoods with the highest incomes as compared to the lowest.
- A greater percentage of people with epilepsy lived in **urban regions (87.4%) than rural (12.6%)**. This distribution was similar to the general population in Ontario (2011) which was 86% urban and 14% rural<sup>1</sup>.
- The prevalence of epilepsy in Ontario was not consistent from region to region of the province. There was a **1.6-fold variation in the cumulative prevalence of epilepsy across the local health integration networks (LHINs)**. The 15-year prevalence ranged from 5.2 per 1000 in the Central LHIN to 8.4 per 1000 in the Erie St. Clair and South East LHINs.

## Health care costs and services:

- The health care costs in the report for individuals identified with epilepsy were all contacts with the health system, for whatever reason, and not just the costs related to the care or treatment of epilepsy. The health care costs captured in this study represent about 85% of the costs paid for by the Ontario Ministry of Health and Long-Term Care (MOHLTC). Some of the MOHLTC costs are missing, such as appointments with specialists in hospital out-patient clinics, out-patient diagnostic tests and out-patient imaging. It is important to note that the study did not capture services and treatment costs that were paid for privately or those paid for by other provincial ministries.
- In 2010/11, the **average one year health care cost per person** identified with epilepsy was **\$7,283** and **the most frequent annual cost was \$1,124**. As stated previously, this only includes costs paid for by the province and does not account for health care costs paid by individuals out-of-pocket or through private insurance. For example, the costs of antiseizure drugs for most people under age 65 were not included since drug costs were only captured from individuals who were eligible for one of Ontario's public drug programs.

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<sup>1</sup> Population, Urban and Rural, by Province and Territory (Ontario). *Government of Canada, Statistics Canada*. Accessed July 8, 2015 at [www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo62g-eng.htm](http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo62g-eng.htm)

- The **average one year health care cost per person with a new diagnosis** of epilepsy was **\$10,631** and the **most frequent annual cost for incident cases was \$1,790**.
- There was a **wide range of health care costs** for individuals identified with epilepsy. There were a proportion of people with epilepsy, within all age groups, who had significantly higher health care costs and this raised the overall average. The mean or average health care cost is not representative of the majority of people with epilepsy in most age groups (with the exception of people 75 years and older). Further information is needed to understand the factors that contribute to the huge range of health care costs in people with epilepsy. One potential factor to consider is that people with drug-resistant epilepsy have higher needs for health services compared to individuals with well-controlled seizures<sup>2</sup>. The influence of co-existing health conditions is another factor to consider.
- There were also differences in **health care costs** depending on the age group. Annual costs tended to increase with age and were **highest for seniors**. Long-term care accounted for 28.7% of the total health care costs in people with epilepsy who were 65 years and older.
- Within the pediatric population, health care costs were **highest for infants and young children** (0 to 4 years of age).
- **Over 50% of the health care costs** for individuals identified with epilepsy were attributable to **hospital care** (35.5%) and **physician and other health care professional services** (16.9%). During the first year after diagnosis, nearly two-thirds of the MOHLTC costs were attributable to these two health system services with 46.1% associated with hospital care alone.

## Overview

This report is a good starting point to understand the impact of epilepsy and other brain disorders in Ontario using population-based health information.

- This study provides information about the epidemiology of epilepsy that is specific to our province.
- The demographic profile of the prevalent cases provides new information about the distribution of people with epilepsy by age group, geographic region and neighbourhood income.
- The data on health system utilization also provides new information about the types of health services used by people who have epilepsy and costs to the MOHLTC.
- The incidence rate and prevalence from this study are consistent with ranges previously reported for North America<sup>3</sup> as well as those reported in a recent overview<sup>4</sup> of the National Population Health Study of Neurological Conditions.
- The annual incidence was relatively stable over six years (2004/05-2010/11) at about 0.45 per 1000.

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<sup>2</sup> Begley CE, Famulari M, Annegers JF, Lairson DR, Reynolds TF, Coan S, Dubinsky S, Newmark ME, Leibson C, So EL, Rocca WA. The cost of epilepsy in the United States: an estimate from population-based clinical and survey data. *Epilepsia*. 2000. 41(3):342-51.

<sup>3</sup> Theodore WH, Spencer SS, Wiebe S, Langfitt JT, Ali A, Shafer PO, Berg AT, Vickrey BG. Epilepsy in North America: a report prepared under the auspices of the Global Campaign Against Epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. *Epilepsia*, 2006. Accessed July 8, 2015 at [www.ilae.org/Visitors/Chapters/documents/usa.pdf](http://www.ilae.org/Visitors/Chapters/documents/usa.pdf)

<sup>4</sup> Mapping Connections: An Understanding of Neurological Conditions in Canada. Ottawa, ON: Public Health Agency of Canada; 2014. Accessed July 8, 2015 at [www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/assets/pdf/mc-ec-eng.pdf](http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/assets/pdf/mc-ec-eng.pdf)

- The prevalence of epilepsy varied depending on the time period studied, from 5.2 per 1000 at the shortest duration (9 years) to 6.8 per 1000 at the longest duration (15 years). Further information is needed to determine the best sampling period for epilepsy prevalence when using health administrative data.
- This report did not show incidence data by age although the age profiles of the prevalent cases were presented. Previous research from other developed countries has reported that the pattern of new onset epilepsy is bi-modal with the highest number of new cases seen during early life (infants and young children) and in seniors. It would be interesting to see the incidence data from this study, by age, in order to compare the Ontario findings with other jurisdictions.

## Suggestions for Future Research

This report identifies some additional areas that need to be addressed.

The study provides information about the 1-year health care costs for people who have brain disorders in Ontario from the perspective of the Ministry of Health and Long-term Care.

Epilepsy can begin at any age and can be lifelong. Estimates of the cumulative economic burden of epilepsy over the course of a lifetime are necessary in order to understand the true health care costs of this brain disorder.

Understanding health care costs in more detail will be extremely important and an area that needs further exploration is whether health system use related to epilepsy, or a co-morbid condition, can be differentiated from the health care services that people receive for reasons that are unrelated to epilepsy.

The additional health care costs that are not captured by administrative health data are important to quantify as well. The health care and treatment costs that people pay out-of-pocket as well as the costs paid by third party insurers contribute to the overall financial impact of epilepsy and other brain disorders in Ontario.

People with epilepsy will have different responses to treatment. A general finding in past research has been that approximately two-thirds of people with epilepsy become seizure-free with antiseizure medication and one-third have drug-resistant epilepsy. Understanding the differences in health system utilization associated with having drug-resistant epilepsy as compared to epilepsy that is well-controlled would provide additional information about the impact of epilepsy and also help inform program planning and resource allocation. It would also be helpful to differentiate the demographic profile according to response to treatment in order to understand if there are any age-related differences, regional differences or differences in measures of socioeconomic status.

Epilepsy is a lifelong disease for many people but not for everyone. Epilepsy can resolve over time, as a result of an intervention (e.g. surgery), or with changes during development and some people no longer require treatment to remain seizure-free. Future long-term surveillance and population-based studies of epilepsy will require a way to differentiate individuals who have active epilepsy, whether their seizures are controlled or uncontrolled, from individuals whose epilepsy is resolved. However, it may still be helpful to continue to monitor health system utilization and costs for people whose epilepsy is resolved since co-morbid conditions may persist.

Previous research has indicated that the direct health care costs are a small fraction of the total financial impact of epilepsy and that the indirect costs, such as impacts on employment due to disability, account for the lion's share of the financial burden of this condition. Additional research is needed to understand the full impact of epilepsy both on the day to day lives of people and their families as well as for society as a whole.