



Traumatic Brain Injury: A Lifelong Condition

Moderate to Severe Brain Injury as a
Chronic Condition

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The position paper presented here is intended as a living document and should be regarded as such. It does not aim to represent all views or encompass the breadth of perspectives found in the many excellent sources of information available. As new evidence emerges and the landscape of knowledge evolves, this position paper will be updated accordingly to ensure its relevance and accuracy.

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INTRODUCTION

Calling on the Government of Canada to Designate Moderate to Severe Traumatic Brain Injury a Chronic Condition

A moderate or severe traumatic brain injury (TBI) is a devastating event—not only in the instance it occurs, but for most individuals, in the years that follow. This single event triggers a chronic condition, a process that results in varied and complex care needs.

A serious TBI occurs when there is a sudden physical impact to the head causing damage to the brain tissue encased in the skull. Although milder forms of TBI such as concussion exist, this position paper focusses on moderate to severe TBI given these brain injuries represent those with the highest prevalence of debilitating life-changing effects.

This document presents an overview of the impact of TBI as a chronic condition, which is an under-recognized public health concern affecting over 165,000 Canadians, their families, and communities. By acknowledging TBI as a chronic condition, Canada's health and social systems can access updated data for better tracking of incidence, prevalence, mortality, healthcare utilization (e.g., hospitalizations, physician visits), and co-existing health conditions. This recognition will enable Canada to address these pressing health priorities, including mental health, addictions, and homelessness.

According to a 2020 Public Health Agency of Canada review, between 2002 and 2016, approximately 235,471 injury deaths occurred in Canada, and 22.6 % of these (53,200 deaths) were associated with a TBI diagnosis. Notably, TBI mortality rates were highest among Canadians aged sixty-five and older.

The same report showed that between 2006/07 and 2017/18, there were 399,376 hospitalizations for head injuries, 63 percent of which involved males. The leading cause of hospitalization for head injuries was falls, with rates highest among seniors, particularly those over 85 years of age.

The impact of moderate to severe TBI varies depending on the individual, but is often marked by lasting cognitive, behavioural, emotional, and physical disabilities. Many of these effects may be invisible, which leads to a host of daily challenges for the individual—the least of which are stigma, isolation, and a reduced quality of life.

All TBIs can be debilitating and result in headaches, dizziness, and confusion, while moderate and severe TBI most often requires ongoing medical, rehabilitation, and psychological support -- for memory loss, attention deficits, problems with communication, behavioural and emotional problems, decreased mobility and the need for assistance with activities of daily living such as feeding, bathing and toileting.

Traumatic brain injury impacts more than the injured individual—family members experience on-going stress, both emotionally and financially. Caregivers often need time off work to care for their loved ones, which results in lost income and increased financial stress. The emotional toll and mental stamina are immeasurable for the individual entrusted to the daily care of someone with a chronic condition.

And while family members and caregivers experience emotional distress and burnout caring for someone with TBI, the impact ripples through an individual's social and community networks -- at the time of injury, and for the rest of their lives.

Canadians living with moderate to severe TBI are at greater risk of homelessness, incarceration, unemployment/underemployment, living in poverty, and struggles with mental health and substance use. All face major obstacles in accessing appropriate long-term care and support.

Unlike a broken bone or a torn ligament, a serious TBI is not a one time injury with a linear recovery; rather, it is a chronic neurological condition leading to significant lifelong disability.

At Brain Injury Canada, we provide advocacy and education for the tens of thousands of Canadians living with moderate to severe TBI who require ongoing support and care from health care professionals and family members. The needs of these individuals extend far beyond regular medical check-ups and rehabilitation appointments such as physiotherapy, speech therapy, and occupational therapy. Many individuals also require assistance with activities of daily living, such as dressing, bathing, and meal preparation.

Brain Injury Canada is calling on the Canadian Government to classify moderate to severe traumatic brain injury as a chronic disease under the Canadian Chronic Disease Surveillance System. We do so in partnership with the Canadian Traumatic Brain Injury Research Consortium. This accomplished network of clinician-scientists and researchers, in collaboration with international TBI scientists, are engaged in innovative discoveries in the prevention, diagnosis, prognosis, monitoring and treatment, of Canadians with moderate to severe TBI.

Our policies, services, and supports must keep pace with these innovations and be made available to all Canadians living with TBI, their families, caregivers, and the people/ organizations that provide care after they are released from the hospital and rehabilitation centres.

An important, and achievable, first step is to classify moderate to severe traumatic brain injury a chronic health condition under the Canadian Chronic Disease Surveillance System. This designation will improve data collection and open the door to improved health outcomes for the more than 165,000 Canadians who sustain a TBI every year, and for the hundreds of thousands of individuals already living with a TBI.



MICHELLE MCDONALD

Chief Executive Officer,
Brain Injury Canada

Personalized medicine is revolutionizing TBI management by focusing on individualized approaches

As it is around the world, moderate-severe TBI is a leading cause of death and disability in Canada. Survivors often require lifelong care and support due to the profound and lasting effects on an individual's physical, cognitive, and emotional functioning.

Indeed, over a decade ago, researchers pointed out that TBI should be considered as “the beginning of a chronic disease process, rather than an event or final outcome.” Their aim was to support appropriate clinical management of patients, and to foster research aimed at pre-empting disease processes months and years after the TBI. Since then, the recommendation has gained considerable recognition and traction.

This is why the Canadian Traumatic Brain Injury Research Consortium fully supports the need to classify moderate to severe TBI as a chronic condition rather than an acute, one-time injury.

While progress has been made in the acute management of TBI in recent years, there is still much to be learned about this complex and multifaceted injury. Recent strides in clinical and basic research are critical to improving the management of moderate and severe TBI.

Canadian scientists are developing new tools to measure and determine the severity and prognosis of moderate to severe TBI. These tools go beyond the traditional Glasgow Coma Scale, which was developed in the United Kingdom in 1974 and assesses impairment based on the level of consciousness at the time of injury.

Promising research is underway in the development of more effective treatments and interventions for TBI, including drugs, clinical management and rehabilitation. Scientific research is helping to explain why earlier approaches are not always effective, and why many individuals with TBI continue to experience ongoing symptoms and challenges long after they sustain the injury.

Our work is helping to identify novel monitoring technologies and treatments that will improve outcomes for individuals with TBI over their lifespans.

Research in basic science is critical to our understanding of the mechanisms of TBI and to identify new targets for therapies. Our teams are studying the role of inflammation and repair in TBI and how they contribute to ongoing brain damage, neurological deficits and recovery. By understanding the mechanisms of TBI at a cellular and molecular level, researchers are identifying new modes of intervention and more effective treatments.

Personalized medicine is revolutionizing TBI management by focusing on individualized approaches. Given the intricate nature of TBI and its diverse impact on individuals, genetic makeup plays a crucial role in determining the most effective interventions. Utilizing advanced imaging techniques and biomarkers, researchers can pinpoint specific variations in the nature and severity of TBI. This enables the customization of treatment plans to suit each individual's unique needs.

Collaborative research groups, like the Canadian Traumatic Brain Injury Research Consortium, have spearheaded large-scale multicenter international clinical trials aimed at transforming bedside practices. However, the number of conducted trials testing promising TBI interventions remains limited, and current practices rely on limited evidence, necessitating the evaluation of high-quality clinical trials.

By employing these innovative trial methods, we can enhance our understanding of interventions and expedite advancements in this field. Recent advancements in clinical trial methodology, including Bayesian approaches and platform trials, have ushered in a new era for testing interventions along the care pathway of TBI patients.

By classifying moderate to severe TBI as a chronic condition under the Canadian Chronic Disease Surveillance System, our multi-disciplinary teams can examine all aspects of both the acute phase of the brain injury and the long-term consequences for individuals living with TBI. Our goal is to not only understand why they experience various levels of recovery, but how we can also work more closely with patients, their families, and populations at risk to significantly improve the quality of their lives.



DR. JAMIE HUTCHISON
Co- Chair
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My severe brain injury just didn't happen to me. It happened to my whole family. My husband suddenly didn't have his wife, and our children didn't have their mother. The injury never goes away, and you are never the same person you once were.

-- Barb Butler, Regina, Saskatchewan; Injured in a motor vehicle accident in 1993



The layers of loss following a brain injury and the uniqueness in the realm of grieving are overwhelming for many. To adequately grieve these layers of loss, it requires those involved to explore and determine what the primary and secondary losses of the brain injury are and how this impacts them.

This applies to both the survivor and to their loved ones. Once the layers are identified, then people can begin to work through their feelings. Reflect on the life losses that have you have experienced, including brain injury.

Loss associated with brain injury could be physical and/or cognitive, but there may also be additional losses in relationships, lifestyle, employment, and in the person's sense of self. Each loss requires reflection, expression, and acknowledgment so the person can heal and accept their new life.

-- From "Change of Mind: One Family's Journey through Brain Injury" by Janelle Breese-Biagioni, a memoir that chronicles the author's family's journey through her husband's TBI

EXECUTIVE SUMMARY

The World Health Organization (WHO) defines chronic disease as having one or more of the following characteristics: permanence, non-reversible pathological alterations as the cause, requiring patient training for rehabilitation, and/or an extended period of observation, supervision, or care (World Health Organization, 2002).

Moderate to severe traumatic brain injury (TBI) is the leading cause of death in **adults under 40**, children and youth, but it can affect individuals of any age. TBI results in various impairments, including cognitive, behavioral, physical, and emotional difficulties that hinder independent functioning and daily activities.

These impairments encompass memory loss, difficulty concentrating, fatigue, headaches, seizures, mobility issues, and changes in mood and behavior, among others. Moderate to severe TBIs have long-lasting effects that persist throughout an individual's lifetime post-injury.

By officially recognizing TBI as a chronic condition within the ***Canadian Chronic Disease Surveillance System***, the Canadian government and provincial/territorial health systems can gather data to ensure individuals with TBI receive continuous medical care, support, and rehabilitation services to manage their long-term effects.

CHRONIC NATURE OF MODERATE TO SEVERE TBI

Symptoms of moderate to severe TBI often persist long after the initial injury and necessitate ongoing medical care and support. There is growing recognition that moderate to severe TBI can lead to progressive neurodegenerative processes, similar to other disorders like Alzheimer's disease and Parkinson's disease, due to brain damage and changes in structure and function as individuals age.

FISCAL IMPACT OF MODERATE TO SEVERE TBI IS SUBSTANTIAL

The fiscal impact of TBI on the Canadian healthcare system is difficult to measure given the scarcity and gaps in surveillance data, but the costs are significant. According to a report published by the Canadian Institute for Health Information in 2019, chronic disease management accounted for approximately 67% of total healthcare expenditures in Canada. This includes direct costs related to physician visits, hospitalizations, medications, and other healthcare services.

Furthermore, chronic diseases contribute to indirect costs such as loss of productivity, absenteeism from work, and disability. These indirect costs can have a significant impact on both individuals and the overall economy.

For individuals with a chronic TBI condition, the costs arise from an array of factors, the least of which are the acute hospital length-of-stay, neurosurgery, prolonged coma periods, extensive therapy sessions in hospital and community, and the subsequent loss of productivity due to the patient's inability to perform work-related tasks.

The responsibility for funding TBI patient care is mostly distributed among various entities, including individuals and their families, workers' compensation programs, and government institutions at the federal, municipal, and provincial levels. However, numerous provinces lack a unified strategy or planning division for TBI, resulting in dispersed services among various ministries, including health, workers' compensation, community social services, education, and training. This dispersion highlights the intricate challenge of coordinating and financing TBI care throughout Canada.

HELPING CANADIANS UNDER THE CANADIAN CHRONIC DISEASE SURVEILLANCE SYSTEM

Classifying TBI as a chronic condition under the *Canadian Chronic Disease Surveillance System* acknowledges the high incidence of traumatic brain injury, as well as its significant economic burden on individuals, the healthcare system, and society.

By recognizing TBI as a chronic condition, the health and social systems in Canada will have updated data to accurately track incidence and prevalence, mortality rates, healthcare utilization (such as hospitalizations and physician visits), and multimorbidity and comorbidity.

With up-to-date data, research gaps can be identified that hinder the development of effective treatments for the long-term effects of TBI. Longitudinal studies that follow individuals with TBI over time can provide insights into the natural progression of the injury and identify interventions that improve outcomes.

This position paper serves as a call to action by Brain Injury Canada and the Canadian Traumatic Brain Injury Research Consortium, urging government officials to classify moderate and severe TBI as a chronic condition under The Canadian Chronic Disease Surveillance System.



Hugh and Rosemary (Finlay) use his favourite songs to get Scott (their adult son with a severe TBI) in the mood to stand to get into bed, which he does with the aid of a specialized wheelchair every morning, afternoon and night. There's a floor-to-ceiling steel pole, like a fireman's pole, beside his bed. It's covered in strips of white tape to help Scott get a grip.

His parents usually feed him. Sometimes, he feeds himself. But Hugh and Rosemary have to watch closely because he tends to eat too fast.

-- Excerpt from "When love runs out of time: Parents fear for injured son" by Randy Starkman, Toronto Star, March 3, 2011

MODERATE TO SEVERE TRAUMATIC BRAIN INJURY IN CANADA

Acquired brain injury (ABI), a designation that includes TBI, refers to any damage to the brain that occurs after birth and is not related to a congenital or a degenerative disease. TBI is caused by trauma, an external and forceful impact(s), that damages the brain tissue. According to the Public Health Agency of Canada, an estimated 165,000 Canadians suffer from a traumatic brain injury each year.

In Canada, the most common causes of moderate to severe TBI are:



Falls: Falls are the leading cause of TBI in Canada, accounting for more than **50%** of all cases. They are most common among children and seniors, but they can happen to anyone. Falls from significant heights, such as from ladders or roofs, are particularly likely to result in severe TBI.



Motor vehicle accidents: Motor vehicle accidents are the second leading cause of TBI in Canada. They are most common among young adults aged 15-24 and are often the result of high-speed collisions or accidents involving motorcycles and cars.



Sports: Sports-related TBI is also a significant cause of moderate and severe TBI in Canada, particularly among children and adolescents who play contact sports like football or hockey. Sports-related activities were the leading cause of TBI hospitalizations among children and youth aged 5 to 19 years, accounting for **45%** of all TBI hospitalizations in this age group.



Assaults: Assaults—including intimate partner violence and criminal assaults—are another cause of TBI in Canada, accounting for a considerable number of moderate to severe TBI cases.

Traumatic brain injury also results from workplace injuries and military combat. It is prevalent in all age ranges and socioeconomic groups.

According to the most recent data from Statistics Canada, there were approximately 61,000 hospitalizations for TBI in 2016-2017, with falls being the most common cause of TBI, followed by motor vehicle accidents and assaults. A 2018 study by the Public Health Agency of Canada showed that the severity of TBI is increasing among older adults, with falls accounting for over half of all cases. The use of neurosurgical interventions for TBI has increased, particularly among those with severe injuries.

Historically, mortality for TBI in Canada is high, with a study from the 1980s reporting a rate of 40 % for severe TBI patients. There is also a higher risk of premature death among individuals with TBI, with studies suggesting that TBI associated with increased mortality from a variety of causes, including suicide and accidental injuries.

Ongoing research and development of new interventions will improve the prognosis and quality of life for individuals with moderate to severe TBI in the future and reduce costs to the health system in general.

In terms of additional complications, TBI patients are at increased risk for several health problems, including seizures, cognitive impairment, depression, anxiety, and substance use disorders. Interventions in moderate to severe TBI typically involve a multidisciplinary approach, with a focus on preventing secondary brain damage, managing symptoms, and promoting recovery.

This may include surgical intervention, non-pharmacological medical intervention, drugs, rehabilitation, and monitoring. In recent years, there has been increasing interest in the use of non-pharmacological interventions for TBI in the subacute and chronic phase, such as cognitive rehabilitation, physical therapy, and alternative therapies like acupuncture and mindfulness meditation, although supported by limited evidence.



My son Justin was seventeen when he suffered a severe traumatic brain injury 16 years ago. Every day is a struggle. You grieve for your loved one all the time. But we made sure Justin did rehabilitation every day. It takes such a toll on the whole family – every day, year after year. Justin can only work a few hours a week, and he needs a support worker with him, but with support, positivity, and love, he is now counselling other people with traumatic brain injuries.

-- Suzanne McKenna, mother of Justin McKenna, living with TBI, outside Ottawa

The following is an overview of the general guidelines for managing moderate to severe TBI in Canada:



THE ACUTE PHASE, WHICH IS MANAGED IN-HOSPITAL CRITICAL CARE UNITS:

- The initial focus is on stabilizing the patient and preventing secondary brain damage.
- The patient is assessed using standardized neurological scales to determine the severity of the injury and guide treatment decisions.
- Emergency and Critical care medical treatment may include airway management, oxygenation and respiratory support, blood pressure management, and intracranial pressure monitoring and control, and ensuring adequate cerebral blood flow.
- Neurosurgical interventions may be necessary to address intracranial bleeding, swelling, or other complications.
- The patient is monitored closely to manage complications and prevent secondary brain damage.
- Acute rehabilitation with physical therapy is performed to prevent contractures and motor limitations secondary to immobilization.



THE SUB-ACUTE PHASE, WHICH IS MANAGED THROUGH IN-HOSPITAL REHABILITATION PROGRAMS:

- Rehabilitation is initiated as soon as possible to promote recovery and minimize functional deficits.
- Physical therapy, occupational therapy, and speech and language therapy may be used to address motor, cognitive, and communication deficits.
- Psychological and social support is provided to address emotional and behavioural issues.



THE CHRONIC PHASE, WHICH IS MANAGED THROUGH CO-ORDINATED AND ONGOING INTERVENTIONS BY MULTI-DISCIPLINARY CLINICAL TEAMS (DEPENDING ON LOCATION AND SERVICE AVAILABILITY):

- The focus is on long-term maintenance and monitoring of the patient's physical, cognitive, and emotional health.
- The patient may continue to require ongoing rehabilitation and support to manage chronic symptoms and functional deficits.
- Medication management may be necessary to address seizures, pain, spasticity, or other chronic issues.
- The patient will require ongoing monitoring for progressive complications and neurodegeneration related to aging, early dementia, hydrocephalus, or other medical conditions related to the TBI.

LIVING WITH MODERATE/SEVERE TRAUMATIC BRAIN INJURY

The acute consequences of moderate to severe TBI will typically show rapid improvements within the first months of injury. However, recovery tapers and reaches a plateau by one to two years that is often well below a person's pre-injury level.

The range of impairments and other associated medical effects affect daily functioning, independence, and integration back into pre-injury like work, school, sport and parenting:



Cognitive impairment: Problems with attention, learning and memory, ability to process information quickly, communication, processing of visual and spatial information, problem-solving, judgement, planning and follow-through, self-awareness



Physical and sensory impairments: Problems with physical strength (including paralysis), coordination, pain (e.g., headaches), sensory disturbances, hearing and/or vision loss



Behavioural changes: Impulsivity, uncontrolled anger and aggression, and disinhibition



Emotional changes: Emotional lability (e.g., crying unexpectedly), mood disorders (depression) and anxiety



Sleep disorders: TBI disrupts normal sleep patterns, leading to difficulties falling asleep or staying asleep and resulting sometimes in debilitating fatigue



Brain injury is not an event or an outcome. It is the start of a misdiagnosed, misunderstood, under-funded neurological disease.

**- Dr. Carolyn Lemsky, Neuropsychologist and Clinical Director,
Community Head Injury Resource Services of Toronto**



Social and financial impacts:



Reduced quality of life: TBI leads to a significant reduction in an individual's quality of life due to physical, cognitive, and emotional impairments.



Loss of employment and income: TBI makes it difficult or impossible for individuals to work, resulting in loss of income and financial strain. One in three adults living with moderate/severe brain injury identify challenges with managing money and/or paying bills. Financial struggles and unemployment are cited as the most significant unmet rehabilitation needs and barrier to community participation.



Increased health care costs: TBI requires ongoing medical care, rehabilitation, and medication, which can be cost-prohibitive over the course of a lifetime.



Caregiver burden: TBI places a major burden on family members and caregivers, who are needed for ongoing support and care.



Social isolation: TBI can lead to social isolation and difficulty maintaining relationships, which further impacts an individual's quality of life.

BRAIN INJURY AS A PUBLIC HEALTH PRIORITY

Studies show that moderate to severe TBI is a dynamic condition that can continue to change years after the initial injury. For some individuals, decline occurs over time due to progressive neurodegenerative processes, co-existing health conditions, aging, lifestyle choices, psychosocial factors, and/or systemic barriers.

The chronic nature of TBI should be identified and managed as a lifelong condition to reduce costs to the Canadian health care system, improve health outcomes, increase independent function, and develop participation in society.

There are compelling 'intersectional' ties between moderate to severe TBI and Canadians who are homeless, incarcerated, struggling with mental illness and suicidality, dealing with problematic substance use, living in poverty, or are of Indigenous descent.

Several notable studies by Canadian researchers and scientists shed alarming light on the impacts of TBI on these populations:

Homeless population

Canadian studies have consistently found elevated rates of serious brain injury among people who are homeless or marginally housed. A recent systematic review and meta-analysis conducted by Canadian researchers with data obtained worldwide, including Canada, found that:

- **53 %** of homeless individuals surveyed reported a history of TBI.
- Of those reporting a history of TBI, seven out of 10 reported at least one moderate to severe TBI — significantly higher than the general population where the rate is observed to be 1 in 20 to 30 people with a history of brain injury.
- Falls were the most common cause of TBI reported, followed by assaults and hits on the head.
- Homeless individuals with a history of TBI were more likely to report mental health problems, substance use disorders, and chronic pain.

Although people who are homeless are more susceptible to sustaining additional brain injuries, the majority sustained their injuries before becoming homeless.

The authors of the meta-analysis suggest that TBI screening and interventions should be integrated into homeless health services to improve outcomes and reduce the burden of TBI on this vulnerable population.

Incarcerated population

There is limited data on the prevalence of moderate to severe TBI specifically among inmates in the Canadian prison system. However, some studies have provided insights into the potential impacts of TBI on the incarcerated population:

- A 2018 study conducted in Canada with a small sample of twenty male inmates was conducted by researchers from UBC and the British Columbia Centre for Excellence in HIV/AIDS. The study found that **40%** reported a history of TBI, with **10%** reporting a history of moderate to severe TBI.
- A study done in Ontario showed incidence of incarceration was higher among study participants with prior TBI compared with those without.
- Men and women who had sustained a TBI were about 2.5 times more likely to be incarcerated than men and women who had not sustained a TBI.
- A study conducted in the United States found that **60%** of incarcerated individuals reported a history of TBI, with **43%** reporting a history of moderate to severe TBI.

These studies highlight the relationship between TBI and incarceration and the significant need for more data, education and awareness among our health, social and justice systems.

First Nations, Inuit and Métis Peoples

The prevalence of moderate to severe TBI among Indigenous Peoples in Canada is higher compared to the general population. However, the data is limited. Here are some key findings from the available studies:

- A study conducted in Ontario found that Indigenous individuals were overrepresented in hospitalizations due to TBI, with a higher rate of severe TBI hospitalizations compared to non-Indigenous individuals.
- A 2016 study on the incidence and determinants of traumatic brain injury among the indigenous population in the Terres-Cries-de-la-Baie-James health region of Quebec makes comparisons with other populations: hospital admission data from 2000 to 2012 found the incidence of TBI in this region was significantly higher than in the neighboring non-indigenous population (Nord-du-Québec), but lower than in the neighboring indigenous population of Nunavik.

These studies suggest that Indigenous individuals in Canada are at higher risk of experiencing TBI. This disparity relates to a range of social determinants of health, including poverty, inadequate housing, lack of access to health care, and intergenerational trauma.

Indigenous Canadians face systemic barriers that limit their access to health care services, including geographic and financial barriers, as well as cultural and language barriers. These barriers make it more difficult for Indigenous Canadians to receive the appropriate ongoing and timely care for several chronic health conditions, including moderate to severe TBI.

Mental illness and suicidality

Worldwide studies, including population-based longitudinal studies as well as cross-sectional observational studies, have demonstrated a strong association between brain injury, elevated risk for suicide and mental health disorders. Data from Canadian studies with people of all levels of injury is limited, however, what data does exist points to a clear link between childhood TBI and later difficulties with mental health.

Using data from a population-based survey of middle and high-school students in Ontario, a reported history of TBI of any severity was associated with:

- A **52 %** increase in psychological distress
- A **239 %** increase (2 to 3 times more likely) to attempt suicide
- A **145 %** increase in the likelihood of being prescribed medication for anxiety, depression or both

Another Canadian study found that in people with moderate to severe TBI:

- A significant number showed symptoms of anxiety and depression further along the chronic stages of injury they were (e.g., from 2 months to 3+ years post-injury).
- Younger males were at the highest risk of poor mental health outcomes, and a reduced return to work in these young men.
- A separate Canadian study showed volume loss in the hippocampus after injury, putting people at increased risk of psychosis in the chronic stages of moderate to severe TBI.
- People living with the effects of TBI are more likely to seek assistance in mental health settings. Multi-site surveillance data from the US have found that as many as 19 % of psychiatric inpatients have a known history of moderate to severe brain injury.
- Data from the 2011, 2013, and 2015 cycles of the Ontario Student Drug Use and Health Survey, involving children in grades 7 to 12, linked problem gambling to TBI, in addition to behaviors such as risk-taking, impulsivity, psychological distress, substance abuse, and violent crime.



After my car accident in 2009, I was hearing voices, I couldn't speak. When I went to the hospital, they thought I was drunk and told me to leave. There was no support...I committed a crime so I could go to jail. At least I had a roof over my head and food, and they diagnosed my traumatic brain injury, and got me help.

-- Derrick Forsyth, Victoria, BC, former inmate, recovering addict, living with a TBI

Problematic substance use

Studies have shown that problematic substance use is common in people living with TBI.

- About **20%** of people who survive a traumatic brain injury will develop a new problem with substance use.
- A 2015 study of a sample of Canadian adults found a significant association between a history of TBI and higher rates of current cigarette smoking, substance use, and elevated psychological distress in a sample of Canadian adults. These findings emphasize the importance of considering the history of TBI, especially when treating conditions such as substance abuse and psychological distress.
- A study conducted in the United States found that **22%** of individuals who reported substance use disorders also reported a history of TBI, with **8%** reporting a history of moderate to severe TBI.

Addressing the social determinants of health that impact problematic substance use, such as poverty, homelessness, and trauma, is important in preventing TBI and improving the health outcomes of this population.

Unemployment and Living in poverty

There are several studies linking poverty and low income with increased risk of TBI. A study conducted in Canada found that individuals living in low-income neighborhoods had a higher risk of TBI-related hospitalizations compared to those living in higher-income neighborhoods.

According to the Ontario Brain Injury Association Impact Report on persons living with brain injury, 75% of respondents indicated they were employed before their brain injury. However, 87% indicated that they are not currently employed following acquired brain injury.

Furthermore, studies suggest that individuals living in poverty are at higher risk of experiencing TBI compared to those with higher income levels.

Housing, education, and access to health care are important in preventing TBI and improving the health outcomes of this population, however, like many populations impacted by moderate to severe TBI, data is limited.

Dual diagnosis: spinal cord injury and traumatic brain injury

A large number of patients with traumatic spinal cord injury sustain a moderate to severe TBI at the same time. However, due to the focus on spinal cord injury or other life-threatening injuries that occur, these TBIs are often undiagnosed:

- An Ontario group found that the TBIs of at least **40%** of patients with spinal cord injury were undiagnosed, and that these “dual diagnosis” patients, are at risk of being branded as “difficult”, require greater clinical resources, and need more specialized rehabilitation therapy than patients with spinal cord injury alone.
- Another study by the same group found that, this “dual diagnosis” population made less improvement with rehabilitation and had an increased risk of difficulties with personal and family adjustments in the chronic stages of injury as compared to patients with spinal cord injury alone.

Recognizing the particular needs of these vulnerable patients who endure chronic TBI in addition to a spinal cord injury is essential for improving their clinical outcomes in a number of areas including wound care, mental health, and social isolation.

Neurodegeneration

A growing number of studies reveal that, contrary to prevailing assumptions, moderate to severe TBI triggers a series of adverse changes that result in progressive neurological decline and cognitive decline. These changes take place long after the initial injury due to prolonged neuroinflammation and the delayed death of brain and neurological cells.

- A number of Canadian studies have shown that in the early months and years post-injury, people with moderate to severe TBI show progressive shrinkage of the whole brain and sub-structures (grey and white matter; cortical and sub-cortical), losses to white matter integrity, and reductions in functional connectivity of the brain.
- Canadian studies have also shown progressive declines in cognitive functioning.

Recognizing moderate-severe TBI as a chronic disorder would allow for more research in the preventative treatment of neurodegeneration and help reduce the risk of dementia associated with TBI.



I was in a car accident and a coma for three weeks. The impact of the brain injury never goes away. I have chronic balance issues and have been falling for 30 years.

-- Barb Butler, Regina, Saskatchewan, living with TBI

COSTS OF BRAIN INJURY

The fiscal impact of TBI on the Canadian healthcare system is difficult to measure given the scarcity and gaps in surveillance data, but the costs are significant. According to a report published by the Canadian Institute for Health Information in 2019, chronic disease management accounted for approximately **67%** of total healthcare expenditures in Canada. This includes direct costs related to physician visits, hospitalizations, medications, and other healthcare services.

Furthermore, chronic diseases contribute to indirect costs such as loss of productivity, absenteeism from work, and disability. These indirect costs can have a significant impact on both individuals and the overall economy.

A study using data from the province of Ontario between 2004 and 2007 aimed to estimate the direct costs associated with acquired brain injury (ABI) with a sample of 19,435 individuals with ABI and a comparison group of 38,870 individuals without ABI. The following key findings were reported:

- Individuals with ABI had significantly higher health care costs compared to individuals without ABI. The average annual health care cost per person with ABI was approximately \$23,000, which was more than double the average annual health care cost for individuals without ABI.
- Hospitalizations were the primary driver of health care costs for individuals with ABI, accounting for approximately 60% of the total health care costs.
- Individuals with ABI who required long-term care had significantly higher health care costs compared to those who did not require long-term care.
- Health care costs varied by age and gender, with higher costs observed for males and individuals aged 45-64 years.
- The total annual health care costs associated with ABI in Ontario were approximately \$442 million, representing a significant burden on the health care system.

A study done in the USA in 2011 involved a sample of 518 individuals with TBI and a comparison group of 572 individuals without TBI in Olmsted County, Minnesota, showed:

- **Increased medical care costs** for individuals with TBI were significantly higher in total medical care costs compared to individuals without TBI. These costs were approximately three times higher for individuals with severe TBI, and approximately two times higher for individuals with mild or moderate TBI.
- **Lifetime medical care costs** for individuals with severe TBI were approximately \$3 million, while the costs for individuals with mild or moderate TBI were approximately \$85,000 and \$941,000, respectively.
- **Contributing factors to medical care costs** for individuals with TBI, included hospitalizations, emergency department visits, physician visits, and medication costs.
- **Long-term medical care costs of a moderate/severe traumatic brain injury** remained elevated for individuals with TBI over their lifetime.

A position paper done in 2016 by the Cridge Centre for the Family in British Columbia showed comparative daily costs of care for a TBI patient in an acute care hospital/rehabilitation centre at \$1500, a federal prison at \$323, MacDonald House with 24/7 support at \$253, and Cridge Apartment Housing with support at \$80.

Economic studies on the delivery of community-based support because of the chronic nature of moderate to severe TBI should be a priority for all regions in Canada.



It's time for the provincial and federal governments to focus on the consequences of 30 to 40 years of failed social policy around mental health, addictions, trauma and brain injury.

-- Nanaimo Mayor Leonard Krog, in response to escalating violence in his community

REGIONAL DISPARITIES IN CANADIAN CARE

Access to long-term care varies, depending on where a Canadian with a moderate to severe TBI lives. As with other chronic health conditions in Canada, there are significant provincial and regional disparities in the care and support provided to persons with moderate to severe TBI. The level and quality of care varies depending on the province or territory, as well as the specific region within that province or territory.

Some regions in all provinces and territories have access to specialized rehabilitation services, while others have limited resources and long waitlists, impacting the availability and accessibility of services, such as in-home support, respite care, and community-based programs.

Québec, for example, has an integrated trauma system that mandates referral to rehabilitation centres for all hospitalized patients, including those with moderate and severe traumatic brain injury. All patients have equal access to rehabilitation services and are only transferred back to their respective regions once the available level of rehabilitation support matches that available in major cities.

By designating moderate to severe TBI as a chronic condition under The Canadian Chronic Disease Surveillance System, the provinces and territories will have access to more accurate data on incidence and prevalence, enabling the allocation of appropriate funding for personnel, high-quality care and support for individuals with TBI.



A brain injury is an isolating and lonely experience to no fault of my family and friends who cared for me...one thing became increasingly clear: a TBI is unlike any other injury. Your brain is who you are. When it is changed, it changes everything.

Society wouldn't expect a person with a broken leg to run a marathon with a cast on. TBIs are invisible, and for this reason, in my experience, others often underestimate the effect that they have on survivors' physical, mental and emotional well-being.

If you are someone with a TBI or know someone with a TBI, try to visualize the "cast" on their brain and, most importantly, slow down to walk by their side while they heal.

**-- Chandra Groves, survivor of a TBI sustained in an auto accident in 2018,
Saskatoon**

GAPS IN CANADIAN SURVEILLANCE DATA

It is a challenge to provide real-time or up-to-date information on moderate to severe TBI in Canada due to the significant gaps in data surveillance, including:



Inconsistent data collection methods: Varying data collection methods across provinces and territories can lead to inconsistencies and challenges in aggregating data at the national level. This makes it difficult to accurately assess the full prevalence and impact of TBI in Canada.



Lack of standardized reporting: The absence of a standardized reporting system for TBI cases makes it more challenging to compare and combine data from different health care providers and institutions.



Limited access to rural and remote communities: Data collection in rural and remote areas is less comprehensive due to limited resources and infrastructure, leading to under-reporting of TBI cases.



Under-reporting of moderate to severe TBI occurrences: Many moderate to severe TBI cases are not reported or recorded, leading to an incomplete understanding of how extensive the problem really is.



Incomplete data on long-term outcomes: There is limited data on the long-term outcomes of TBI patients that are patient oriented, such as the overall neurological function. More so for more specific cognitive, emotional, behavioural, and social functioning. Although important, mortality is not the gold standard outcome measure in moderate and severe TBI. This hinders the development of targeted interventions and support programs.



Limited data on vulnerable populations: Certain populations, such as Indigenous communities, homeless or individuals suffering from IPV, are underrepresented in TBI data. This makes it difficult to accurately assess the impact of TBI on these groups and to develop targeted prevention and intervention strategies.



Challenges in data sharing and collaboration: Data privacy and confidentiality concerns limit the sharing of TBI data among health care providers, researchers, and other stakeholders, leading to gaps in knowledge and understanding.

To address these gaps in Canadian surveillance data, it is essential that the Government of Canada establish standardized reporting systems through The Canadian Chronic Disease Surveillance System to improve data collection methods, and encourage collaboration among health care providers, researchers, and policymakers.



(A severe traumatic brain injury) is like being in a foreign country where you don't understand the language, the culture or the customs.

- Ryan Straschnitzki, Canadian hockey player who was paralyzed and suffered a brain injury in a bus crash.

CALL TO ACTION

Moderate to severe TBI should be classified as a chronic health condition under the **Canadian Chronic Disease Surveillance System**, as it is a progressive and long-term condition that has ongoing impacts on cognitive, physical, and emotional health, as well as the quality of life for the injured and his or her family, and community.

This classification will help address the lack of recognition and understanding of TBI as a chronic health condition and ensure health systems have the data to allocate appropriate supports and resources over the life span.



CONCLUSION

Moderate to severe TBI is not a single event, but rather a chronic condition that progresses over time. The ongoing damage caused by TBI results in long-term cognitive, physical, and emotional impairments.

Moderate to severe TBI impacts multiple systems, including the nervous, endocrine, and immune systems. These impacts result in a wide range of symptoms and complications including a progressive neurodegenerative process due to the initial brain damage and changes in brain structure and function as the individual ages.

There is an urgent need for continued research and collaboration to better understand the disease process of TBI and develop new treatments and interventions from the acute phase to the chronic phase.

This includes collaboration among individuals with moderate to severe TBI and their families, researchers, clinicians, community service providers, and policymakers to improve the management of outcomes of those who are injured and improve their quality of life.

There also needs to be an investment in community support and services to ensure people can be supported, valued and engaged in their community over the long term.

Canada has one of the most comprehensive chronic disease surveillance systems in the world, but it is missing a large piece of the puzzle. It is essential for the Government of Canada and the Canadian Chronic Disease Surveillance System to designate moderate to severe TBI as a chronic, progressive lifelong condition.

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The collective efforts of these remarkable individuals have helped to assemble as comprehensive and compassionate a document as we can, at this point in time, to guide the future of traumatic brain injury care, support and research in Canada.

By extending the reach of the Canadian Chronic Disease Surveillance System to include moderate to severe TBI -- and through this first critical step, we affirm our commitment to equality, inclusivity, and the well-being of all Canadians.