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Cerebral palsy in Canada, 2011–2031: results of a microsimulation modelling study of epidemiological and cost impacts

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Abstract

Introduction: The objective of our study was to present model-based estimates and projections on current and future health and economic impacts of cerebral palsy in Canada over a 20-year time horizon (2011–2031).

Methods: We used Statistics Canada's Population Health Model (POHEM)–Neurological to simulate individuals' disease states, risk factors and health determinants and to describe and project health outcomes, including disease incidence, prevalence, life expectancy, health-adjusted life expectancy, health-related quality of life and health care costs over the life cycle of Canadians. Cerebral palsy cases were identified from British Columbia's health administrative data sources. A population-based cohort was then used to generate the incidence and mortality rates, enabling the projection of future incidence and mortality rates. A utility-based measure (Health Utilities Index Mark 3) was also included in the model to reflect various states of functional health to allow projections of health-related quality of life. Finally, we estimated caregiving parameters and health care costs from Canadian national surveys and health administrative data and included them as model parameters to assess the health and economic impact of cerebral palsy.

Results: Although the overall crude incidence rate of cerebral palsy is projected to remain stable, newly diagnosed cases of cerebral palsy will rise from approximately 1800 in 2011 to nearly 2200 in 2031. In addition, the number of people with the condition is expected to increase from more than 75 000 in 2011 to more than 94 000 in 2031. Direct health care costs in constant 2010 Canadian dollars were about $11 700 for children with cerebral palsy aged 1–4 years versus about $600 for those without the condition. In addition, people with cerebral palsy tend to have longer periods in poorer health-related quality of life.

Conclusion: Individuals with cerebral palsy will continue to face challenges related to an ongoing need for specialized medical care and a rising need for supportive services. Our study offers important insights into future costs and impacts associated with cerebral palsy and provides valuable information that could be used to develop targeted health programs and strategies for Canadians living with this condition.

Highlights

- A cerebral palsy diagnosis is accompanied by a substantial economic and social burden.
- The number of newly diagnosed cases of cerebral palsy will rise from approximately 1800 in 2011 to nearly 2200 in 2031.
- The number of people living with cerebral palsy is expected to increase from more than 75 000 in 2011 to more than 94 000 in 2031.
- Canadians with cerebral palsy will continue to experience reduced quality of life, increased disabilities and a rising need for supportive services including informal care.

Introduction

Cerebral palsy is the most common cause of motor disability in childhood.[1-3] It is a heterogeneous group of neurological disorders with motor impairments as the core feature. Individuals with cerebral palsy frequently have comorbid conditions that further affect their function.[4] The comorbidities associated with cerebral palsy contribute to individual and family challenges and the financial costs

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related to the medical, rehabilitation and educational needs specific to each child.

Cerebral palsy results from disturbances to the developing brain at any time during pregnancy through early childhood (2 years of age). Congenital cerebral palsy refers to prenatal and perinatal aetiologies before 28 days of life, while postnatal cerebral palsy refers to aetiologies from 28 days of life until 2 years of age. Cerebral palsy has multiple causes, clinical subtypes, associated comorbidities and functional outcomes. The diversity in terms of the onset, neuromotor impairment pattern, severity across functional domains, presence of multiple health conditions or diseases, secondary complications and available interventions makes it nearly impossible to categorize cerebral palsy according to a single classification.[5]

Not surprisingly, multiple risk factors are associated with the condition during the prenatal (prior to labour and delivery), perinatal (during the birthing process) and postnatal (after birth in the first 2 years of life) periods.[3-9] Risk factors include premature birth, intrauterine growth restriction, intrauterine infection/inflammation, male sex, consanguinity, stroke prior to 2 years of age and hypoxic ischemic encephalopathy. Nevertheless, the specific causal mechanism remains elusive for most children with cerebral palsy. Most children are diagnosed in the first 2 years of life,[10] although some diagnoses may not occur until later in childhood.[11,12]

Very little has changed over the past decade in the global prevalence of cerebral palsy.[1-6,8,13-18] A recent meta-analysis reported the birth prevalence of cerebral palsy in developed countries to be 2.11 per 1000 live births.[3] However, population-based studies have reported prevalence estimates ranging from 1.5 to approximately 4 per 1000 live births, and highest in countries with higher incidence of consanguinity.[19-23] The lack of case-validated algorithms for identifying cerebral palsy[24] in administrative health databases may contribute to variability in estimated prevalence as diagnostic code misclassification may be occurring.

The variability in cerebral palsy prevalence estimates across the world and within Canada may also be due to differences in the criteria used for diagnosing the condition,[24,25] as well as differences in pre- and perinatal care in some populations. Studies conducted in Alberta[26], British Columbia[27] and Quebec[28] have reported prevalence estimates similar to the worldwide estimates. Using administrative databases, Alberta reported an estimate of 2.57 per 1000 live births at 8 years,[26] while the figure in British Columbia was 2.68 per 1000 live births.[27] Using data from a Quebec cerebral palsy registry, Oskoui et al.[13] reported an estimate of 2.30 per 1000 children. A more recent Quebec study determined the prevalence of cerebral palsy to be 1.8 per 1000 children (95% confidence interval [CI]: 1.6–2.1), based on data from a cerebral palsy registry versus 2.0 per 1000 children (95% CI: 1.9–2.3) based on data from administrative health databases.[28] Although these estimates are comparable, the concordance in diagnosis between the two databases showed a kappa of 0.62 (95% CI: 0.57–0.67), where a selection bias was seen in the administrative health databases cases.[28] In effect, children with confirmed cerebral palsy who were born preterm were more likely than those born at term to be captured by administrative databases because preterm children tend to receive more specialized developmental care that often leads to correct diagnosis and coding of their condition.

A diagnosis of cerebral palsy comes with a substantial economic and social burden to individuals, families and society in general. The burden can be exacerbated when relevant information for the development of effective health policies, strategies and programs is limited or unavailable. To better understand the incidence, prevalence, impact, health service use and gaps, risk factors and comorbidities of neurological conditions including cerebral palsy, in 2009 the Government of Canada initiated the National Population Health Study of Neurological Conditions (NPHSNC).[29] The NPHSNC included 13 research projects and three national surveys aimed at examining multiple neurological conditions affecting Canadians. One of the projects involved adapting Statistics Canada's Population Health Model (POHEM) framework to create a new population-based longitudinal microsimulation model to project future (up to 2031) health and economic impacts of seven neurological conditions affecting Canadians: this model is called POHEM–Neurological.[29] The NPHSNC set the goal of examining future incidence, prevalence and impact of neurological conditions examined over 5-, 10-, 15- and 20-year horizons. This manuscript focuses on the longest horizon, 20 years, for the model projections.

The objective of our study was to present model-based estimates and projections on current and future health and economic impacts of cerebral palsy in Canada over a 20-year time horizon (2011–2031).

Methods

POHEM–Neurological

The POHEM–Neurological framework is an empirically grounded model that uses Canadian data for demographics and disease incidence and mortality to produce projections over the life cycle of Canadians.[30-34] The model's basic unit of analysis is the individual, or "actor," whose life course is simulated and modelled in continuous time using a Monte Carlo approach.*

The dynamic simulation recreates a synthetic Canadian population at a given point in time (historically and in the future) and ages it, one actor at a time, until each actor's death. Lastly, the model uses status quo assumptions to project future impacts; as such, it assumes that incidence and risk and prognostic factors for the neurological condition being modelled will remain stable throughout the projection period. Further details regarding the methods and procedures involved in POHEM–Neurological can be found elsewhere.[30-34]

The model development process for POHEM–Neurological can be broken into four steps: (1) initialization; (2) yearly updates; (3) model validation; and (4) projection (see Table 1). We used only Canadian, population-based data sources for model initialization and yearly updates.

Step 1: Initialization

Initialization began with historic birth cohorts from 1872 through 2006, which we subjected to the observed historic death rate, as with other Statistics Canada health models.[35,36] Since 1872 represents

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* The Monte Carlo method uses a broad class of computational statistical algorithms that rely on repeated random sampling to obtain numerical results. The essential idea behind the approach is the use of randomness to solve problems that might be deterministic in principle.

TABLE 1
Process for projecting cerebral palsy prevalence, health burden and health care use in Canada using the POHEM–Neurological

	Model-generating step	Model activity	Details of the model step
1	Initialization Generate an initial Canadian population	Initiate a predictive model by creating a synthetic cohort of Canadians.	Historic birth cohorts combined with annual deaths, immigration and emigration. Observed demographic data to 2006 projected to 2031.
2	Yearly Updates Update annual CP incidence and other model parameters	Each year to 2031, update population characteristics, CP incidence, health status and health care costs.	Each year, update the synthetic cohort for demographic changes, CP incidence and deaths. For people with and without CP, estimate Health Utilities Index, health care use (formal and informal) and deaths.
3	Model Validation Validate and calibrate the model	Compare projected CP to observed prevalence in 2009.	Compare projected to observed CP prevalence, by age and sex. Calibrate the model if needed.
4	Projection Generate final projections from 2011–2031	Project CP incidence, prevalence, mortality, health utilities index, HALYs, YLL with CP and health care costs including out-of-pocket expenses and hours of informal caregiving, from 2011–2031.	Generate output tables from projections.

Abbreviations: CP, cerebral palsy; HALY, health-adjusted life year; POHEM, Population Health Model; YLL, years of life lived.

the year of the oldest birth cohort in the LifePaths modelling process,[†] it was used to allow for the simulation and generation of a complete range of ages from newborn to elderly by the year 1971. Hence the model can produce cross-sectional annual tabulations from 1971 that are directly comparable to historical cross-sectional data. For the years 2007 onwards, projected births, deaths and migration (immigration and emigration) used standard Canadian population projections (mid-growth scenario), as estimated by Statistics Canada.[36]

Step 2: Yearly updates of actors' health profiles

An actor's health profile consists of six characteristics: (1) demographics; (2) cerebral palsy status; (3) health status; (4) presence of an informal caregiver; (5) health care costs; and (6) mortality. Each actor's health profile is updated over time, either at an event (e.g. birthday, date of diagnosis of cerebral palsy) or at the change of the calendar year, depending on the profile characteristic. All characteristics were calculated and modelled for people with cerebral palsy and those without neurological conditions. "People with no neurological conditions," as opposed to those without cerebral palsy, was the comparison used because people with cerebral palsy tend to have other comorbid costs that are difficult to separate out (see "Comorbidity, counterfactual population and costs estimation").

Cerebral palsy status: incidence, prevalence and mortality

We applied sex and age-specific cerebral palsy incidence rates to the model's synthetic Canadian population at the beginning of each calendar year. We estimated incidence rates of cerebral palsy using a case identification algorithm that used British Columbia health administrative data from physician billings and hospital discharge abstracts. A case of cerebral palsy was defined as one physician visit or one hospitalization that used the following International Classification of Disease (ICD) codes for cerebral palsy: (1) ICD-10 code G80 (2) ICD-9 code 340; or (3) ICD-9(CM) codes 333.71 or 343. We developed the algorithm with advice from the Canadian Chronic Disease Surveillance System (CCDSS) Neurological Conditions Working Group chaired by the Public Health Agency of Canada.

Based on additional advice from clinical experts in the CCDSS Working Group, we defined incident cases of cerebral palsy as only occurring prior to age 20 years since most children receive a diagnosis in early childhood; after 20 years of age, incidence was assumed to be zero. Incident cerebral palsy cases accumulate over time to generate prevalent cases of cerebral palsy. Relative mortality risks specific to cerebral palsy were applied to actors with cerebral palsy. We estimated sex- and age-specific mortality rates using the same case definition and data used to estimate incidence. The mortality rates specific to cerebral

palsy were divided by the mortality rates for the same sex and age group in the general population, thereby generating a relative mortality risk. In POHEM–Neurological, this relative mortality risk for people with cerebral palsy was multiplied by the baseline mortality rate for the Canadian population. In essence, mortality rates for the cerebral palsy population in British Columbia were compared to the mortality rates of the general population (obtained from Statistics Canada), the latter being a combination of life tables and demographic projections.[36] For future projections, the general population's mortality rate is anticipated to gradually decrease over time, reflecting the projected mortality using birth cohorts and the Lee–Carter model as estimated by Statistics Canada.[37] This means that the projected mortality of Canadians with cerebral palsy decreased at the same rate as for those without cerebral palsy. This is an assumption of the POHEM–Neurological model as it incorporates a parameter that allows for an increase or decrease in the relative mortality risk for people with cerebral palsy compared to those without.

During model validation, the model-projected prevalence of cerebral palsy was much higher than that observed in the British Columbia administrative data (see Figure 1). After consulting with clinical experts on the model-projected prevalence, an adjustment parameter was added to POHEM–Neurological that would remove a diagnosis of cerebral palsy from a

[†] LifePaths is a dynamic longitudinal microsimulation model of Canadian individuals and families that simulates and generates basic individual and family decisions for most discrete events that together constitute an individual's life history. LifePaths creates synthetic life histories from birth to death that are representative of the history of Canada's population.

FIGURE 1
Comparison of 2009 cerebral palsy prevalence rates[a] observed in British Columbia
and POHEM–Neurological model-projected, adjusted and unadjusted parameters
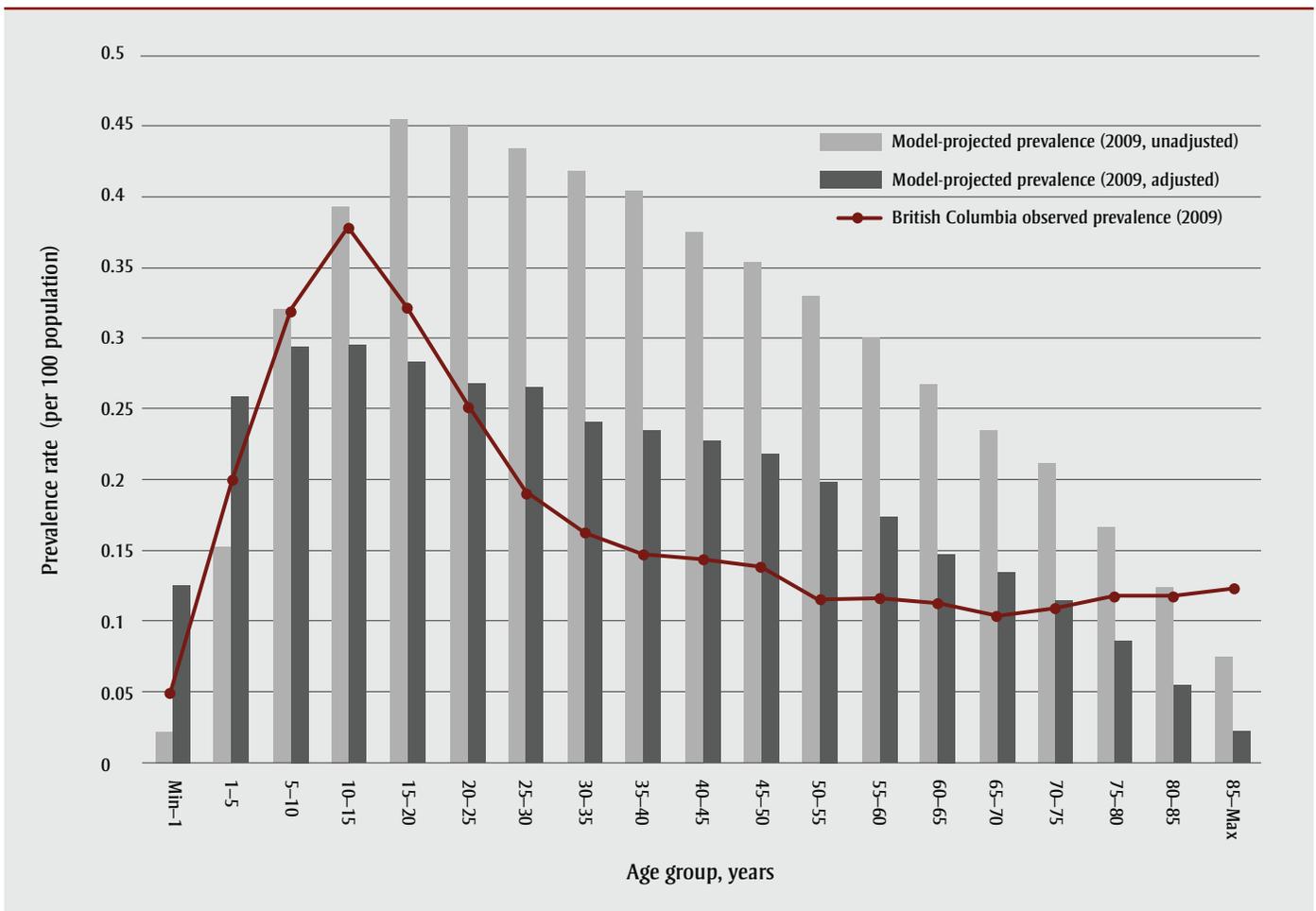
Source: POHEM–Neurological (Statistics Canada and Public Health Agency of Canada).

Abbreviations: Max, maximum age; Min, minimum age; POHEM, Population Health Model.

[a] Since POHEM model's basic unit of analysis is the individual person, it creates a population and ages it, one person at a time, until death. The prevalence estimates from POHEM–Neurological can be considered to be rates because the model calculations took into account the person-years of time contributed by an individual over the calendar year and in the disease state in both the numerator and denominator during the modeling process.

proportion of individuals who had previously been prevalent cerebral palsy cases in the model. Although cerebral palsy is a lifelong disorder, the observed incidence rates likely included a high proportion of false-positive diagnoses in the administrative health data source, such as children who were initially given a cerebral palsy code but who were later given a different diagnosis. Although, the standard error and statistical error of the case definition were not validated for this study, the case definition of a single diagnostic code for cerebral palsy within administrative databases has been validated in the Quebec population and found to be highly specific

but with lower sensitivity. Aligned with this, the prediction model had a much higher prevalence of cerebral palsy predicted, and it was modified to adjust for this difference in sensitivity. Since the validity of diagnostic codes for cerebral palsy in administrative databases has not yet been established,[28] our study methodology can be considered as the best currently available for predicting cerebral palsy in administrative databases in Canada, being as it is highly specific and providing information that is of value.[28] Evidence of misdiagnoses of neurogenetic disorders as cerebral palsy in early life has been recognized.[38] After adjustment (see

Figure 1), the model-generated prevalence "rates"[‡] approached those reported in the literature.[3,19-23]

Health status

The Health Utilities Index Mark 3 (HUI3) is a generic preference-based measure of health-related quality of life that is used to ascertain disease severity.[39] Health-related quality of life is a concept that describes the health of populations and represents a broader health outcome for population health analyses than mortality rates or life expectancy. HUI3 is a utility-based measure that reflects health states with a variety of severity levels, ranging from perfect health

[‡] Since POHEM's basic unit of analysis is the individual person, it creates a population and ages it, one person at a time, until death. The prevalence estimates from POHEM–Neurological can be considered to be rates because the model calculations took into account the person-years of time contributed by an individual over the calendar year and in the disease state in both the numerator and denominator during the modeling process.

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(HUI3 = 1.0) through death (HUI3 = 0). It includes states considered to be worse than death (minimum HUI3 = −0.36).[39] The HUI3 assesses functional health across eight dimensions—cognition, emotion, mobility, dexterity, pain and discomfort, speech, vision and hearing—and provides a valid measure of the functional health status and quality of life experienced by people with cerebral palsy.[39,40] Disability categories have been previously validated for HUI3: none (1.00); mild (0.89 to 0.99); moderate (0.70 to 0.88); and severe (less than 0.70).[41] It should be noted that HUI3 scores can vary depending on the source of valuation, which could either be by proxy or child. A 2019 study[42] reported that HUI3 values can range from −0.013 to +0.84 for children with cerebral palsy. For individuals aged 15 years and older with cerebral palsy, mean HUI3 values (with standard errors) were estimated from the 2011 Survey on Living with Neurological Conditions in Canada (SLNCC).[43] Means were calculated separately for males and females, and for two age groups: 15–34 years and 35 years and older. For children younger than 15 years with a diagnosis of cerebral palsy, a population not covered by the SLNCC, mean HUI3 values were estimated from the 2006 Participation and Activity Limitations Survey (PALS).[44] The estimate was derived for boys and girls combined (i.e. it was not sex specific).

The impact of cerebral palsy can also be assessed by the years of life lost due to the condition, that is, years lost due to premature death from a disease. To calculate years of life lost, we first determined the age of death for all actors with cerebral palsy in each calendar year. Next, we estimated years of life lost for a scenario in which the mortality hazard for cerebral palsy was the same as for actors without cerebral palsy and recalculated the age of death: years of life lost was the difference in age of death between the two calculations. Health-adjusted life years *lost* indicates the years of life lost living in a healthy state, combining morbidity and mortality. Health-adjusted life years (HALYs) were estimated from the product of years of life lived (age at death) multiplied by the annual HUI3 for each actor over their lifetime.

The presence of an informal caregiver

Informal caregiving refers to unpaid care provided by family and friends to Canadians living with a chronic health condition, disability or aging needs.

For each actor in POHEM–Neurological, we assessed the likelihood of having an informal caregiver based on the actor's age, cerebral palsy status and health status (HUI3). If an individual was assigned the presence of an informal caregiver, additional characteristics were assigned based on empirical estimates from the 2011 SLNCC and augmented with the 2012 General Social Survey (GSS)[45]: (1) hours of care received; (2) health status of their caregiver; and (3) out-of-pocket expenses incurred by caregivers.

Health care costs

We estimated formal health care costs in incident and prevalent cohorts with cerebral palsy and ascertained these costs using administrative health data in British Columbia and Ontario. The health care costs were estimated using 2010-dollar values; as such, inflation was not factored into the cost projections. In addition, prevalent and counterfactual cohort costs were obtained for the period 1 April 2009 through 31 March 2010, in both Ontario and British Columbia.

We examined incident cohort costs in Ontario over the same period. We obtained available incident cohort costs in British Columbia for the 12-month period starting on 1 April of the incident year (2006, 2007 or 2008). Formal health care costs were those covered by provincial health plans in health components grouped as follows: (1) acute hospitalization; (2) physician services; (3) prescription drug data;[§] (4) rehabilitation hospitals; (5) Ontario provincially funded home care; (6) Ontario residence and care in a long-term care facility; and (7) Ontario provincially funded assistive devices. Costs included two categories of out-of-pocket costs (expenses paid by an individual but not refunded by insurance or government): those of the patient and those for the caregiver.

Comorbidity, counterfactual population and costs estimation

As noted previously, individuals with cerebral palsy frequently have comorbid

conditions. For instance, one in four children with cerebral palsy have epilepsy, one in two have an intellectual disability, and one in four have a behaviour disorder, including Autism Spectrum Disorder, and other musculoskeletal conditions.[4,47] As such, it is sometimes difficult to isolate the contribution of cerebral palsy to health care costs, caregiving or mortality from those due to comorbidities. To address this issue, we identified a counterfactual (nonneurological condition) population cohort to determine the net impact of cerebral palsy. For example, if the prevalence of comorbidity X is greater in individuals with cerebral palsy than those without, the additional health care costs (or receipt of caregiving hours) associated with this greater morbidity should be attributed to individuals with cerebral palsy. Thus, costs over and above those of the age-sex counterparts without a neurological condition were attributed as being the additional direct cost burden of the neurological condition irrespective of comorbid conditions. Conversely, if individuals with cerebral palsy use less of a particular health care resource than those without a neurological condition, our model should also reflect this lower utilization.

The counterfactual nonneurological condition cohort consisted of all individuals in the respective datasets who had not otherwise been classified as having any of the seven neurological conditions of interest for the NPHSNC microsimulation project, namely Alzheimer disease and other dementias, multiple sclerosis, cerebral palsy, epilepsy, Parkinson disease and parkinsonism, traumatic brain injuries and traumatic spinal cord injuries.

Step 3: POHEM–Neurological validation

The cerebral palsy prevalence "rates" were derived from an unvalidated case algorithm that was used during feasibility studies as part of the NPHSNC (see Figure 1). As such adjustments were made to calibrate the POHEM–Neurological cerebral palsy prevalence projections to align with the widely accepted prevalence benchmark of 2.5 per 1000 live births cited in systematic reviews and literature.[3,19-23] (See "Step 2: Yearly updates of actors' health profiles".)

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§ British Columbia had comprehensive prescription drug cost data for all prescriptions dispensed in community pharmacies, regardless of age, while Ontario had comprehensive data for persons aged 65 years and older with limited data for lower-income cerebral palsy patients receiving provincial support for their disease-modifying therapies. Where we had costs from both provinces, these were weighted based on an input parameter (75% Ontario, 25% British Columbia). The method used for this analysis was based on Wodchis et al.[46]

Step 4: Projection

We projected multiple main model outputs through to 2031 including incident and prevalent cerebral palsy cases in Canada; years of life lived with cerebral palsy; HALY; health care costs including costs for each of the seven sectors; out-of-pocket expenses; and hours of informal caregiving. In addition, we projected three parameters from the perspective of caregivers: hours of caregiving; out-of-pocket expenses; and health status (HUI3).
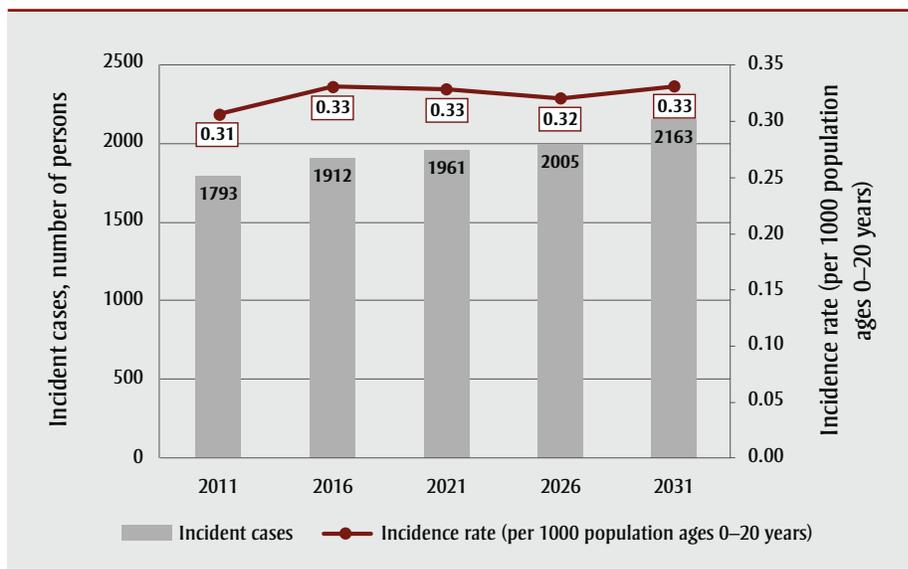
Results

According to POHEM–Neurological projections, the number of children under 20 years of age who will be newly diagnosed with cerebral palsy will increase from approximately 1800 in 2011 to nearly 2200 in 2031 (Figure 2). The rate of cerebral palsy incidence remains stable over the projection period, around 0.3 per 1000 for children less than 20 years old. The majority of the incident cases will occur among children between 1 and 5 years of age, as most cases of cerebral palsy are diagnosed in the first 2 years of a child's life (data not shown).

As with incidence, the number of people with cerebral palsy is expected to increase from more than 75 000 in 2011 to more than 94 000 in 2031, although the prevalence only shows a slight increase over this period, from 2.2 in 2011 to 2.4 per 1000 population in 2031 (Figure 3). The increase can be attributed to the growth of the Canadian population and the increased life expectancy.

In 2011, Canadians with cerebral palsy had reduced functional health (as defined by HUI3 scores) compared with Canadians without neurological conditions. Average HUI3 for Canadians with cerebral palsy was below 0.7, the cut point for "severe disability," at all ages (Figure 4). The average HUI3 for Canadians without a neurological condition was between 1.0 and 0.8; only upon reaching 80 years of age does the average HUI3 score fall below 0.7. The difference in the HUI3 trend remained relatively stable because the model assumes no change in age-specific HUI3 scores.

Given the lower functional health of Canadians with cerebral palsy, the increased demand for informal care is not surprising. A much larger proportion of individuals

with cerebral palsy than those without a neurological condition receive informal caregiving; this holds true at all ages (Figure 5). Overall, individuals with cerebral palsy start to receive informal care at an earlier age, and the proportion receiving informal care rises sharply, remaining consistently higher than among their counterparts without a neurological condition.

People without a neurological condition only begin to require greater amounts of informal care as they approach 70 years of age.

POHEM–Neurological also projects that individuals aged over 35 years will receive considerably more hours of informal care per week than Canadians who do not

FIGURE 2
Projected cerebral palsy incidence cases and rate, ages 0–20 years, both sexes, 2011–2031

FIGURE 3
Projected cerebral palsy prevalence count (person-years) and rate, Canadian population all ages, both sexes, 2011–2031
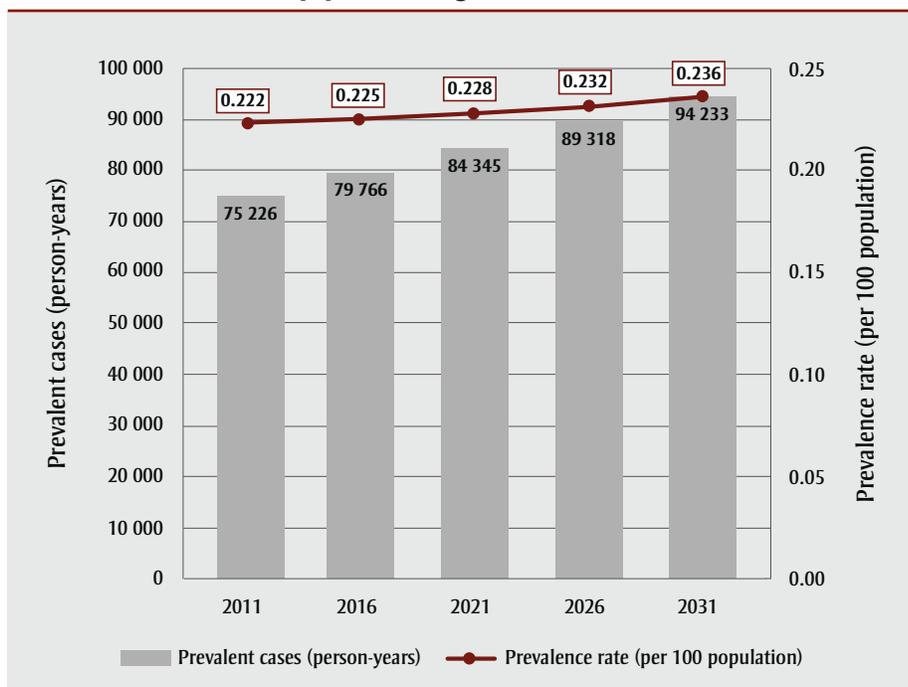
FIGURE 4
Average Health Utilities Index score, by cerebral palsy status and age, 2011
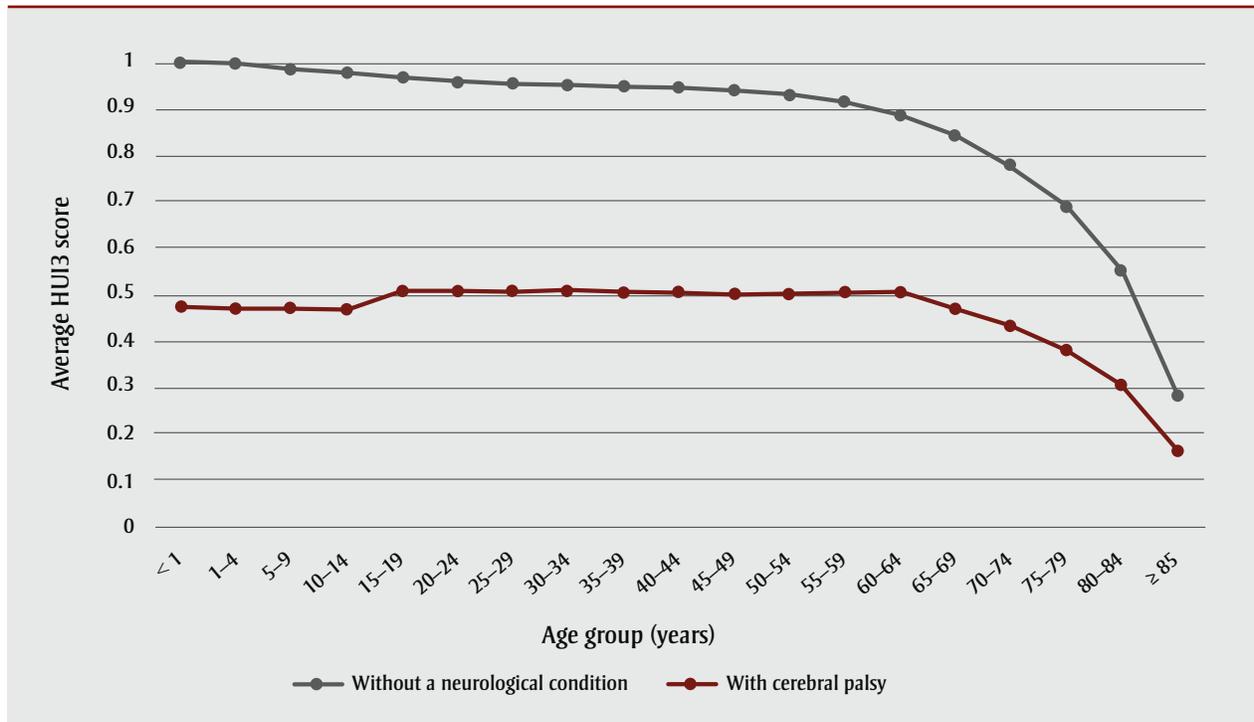
Abbreviation: HUI3, Health Utilities Index Mark 3.

FIGURE 5
Proportion of individuals with an informal caregiver, by cerebral palsy status and age, 2011
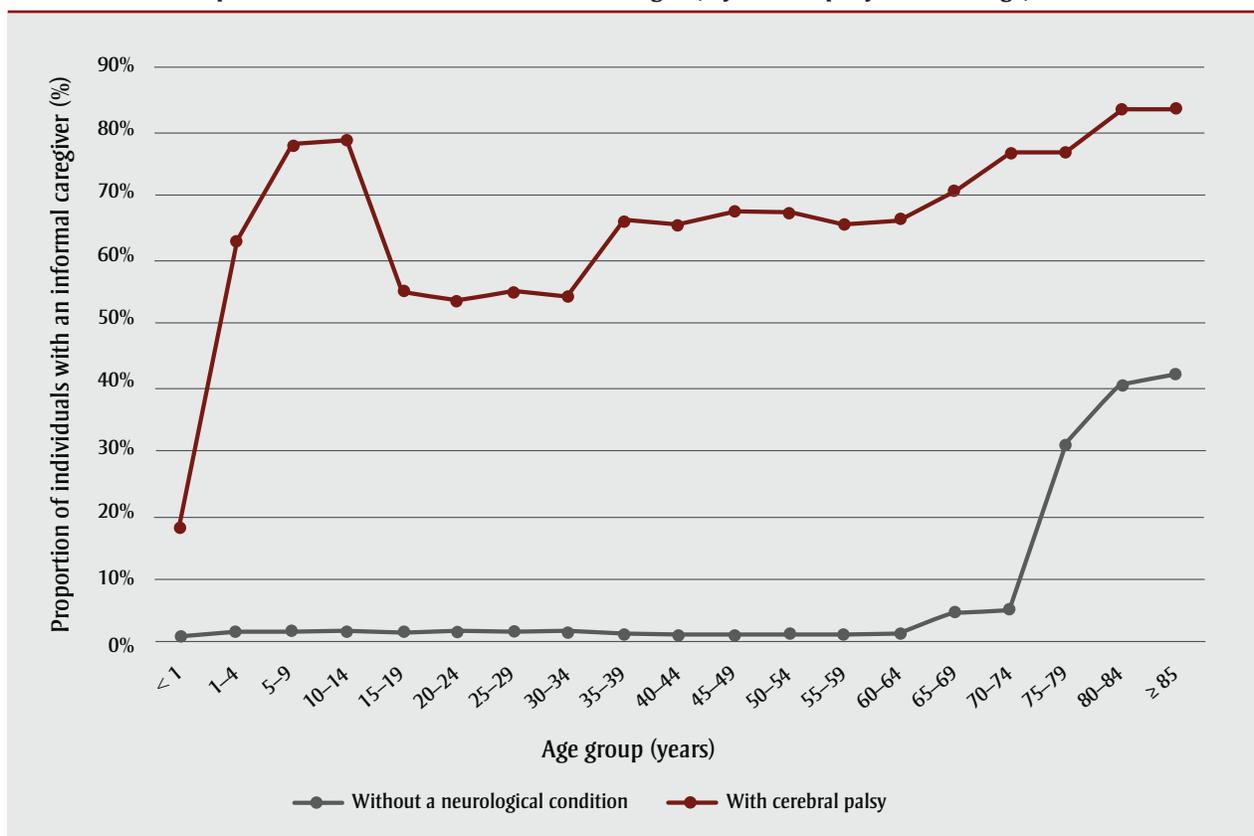
have cerebral palsy, that is, 30 versus 18 hours per week (Figure 6).

We measured years of life lived with a condition and HALYs to assess the impact of cerebral palsy on the quality of life of Canadians. Figure 7 shows years of life lived and HALYs for Canadians with cerebral palsy and their counterparts without a neurological condition, by decade of birth. The model projects that people born between 2010 and 2020 will have longer periods in poor health than their peers without a neurological condition. Women with cerebral palsy are projected to lose, on average, about 41 years of life in good health, while men with cerebral palsy are expected to lose approximately 33 years. In comparison, Canadian women who do not have a neurological condition are expected to lose about 13 years of life in good health while their male counterparts are expected to lose about 11 years.

FIGURE 6
Average number of hours of care received per week among those receiving informal caregiving, by cerebral palsy status, 2011

FIGURE 7
Mean years of life lived and health-adjusted life years, individuals with and without cerebral palsy, by sex and decade of birth

Abbreviations: CP, cerebral palsy; HALY, health-adjusted life year; YLL, years of life lived.

Another important difference between Canadians with cerebral palsy and their counterparts who do not have the condition is that their health care expenditures tend to be higher. Table 2 compares mean p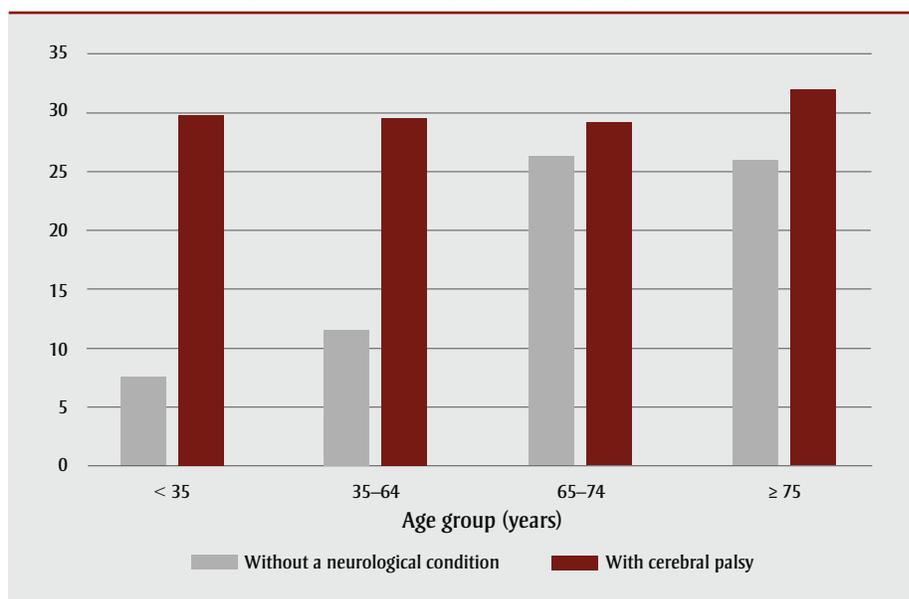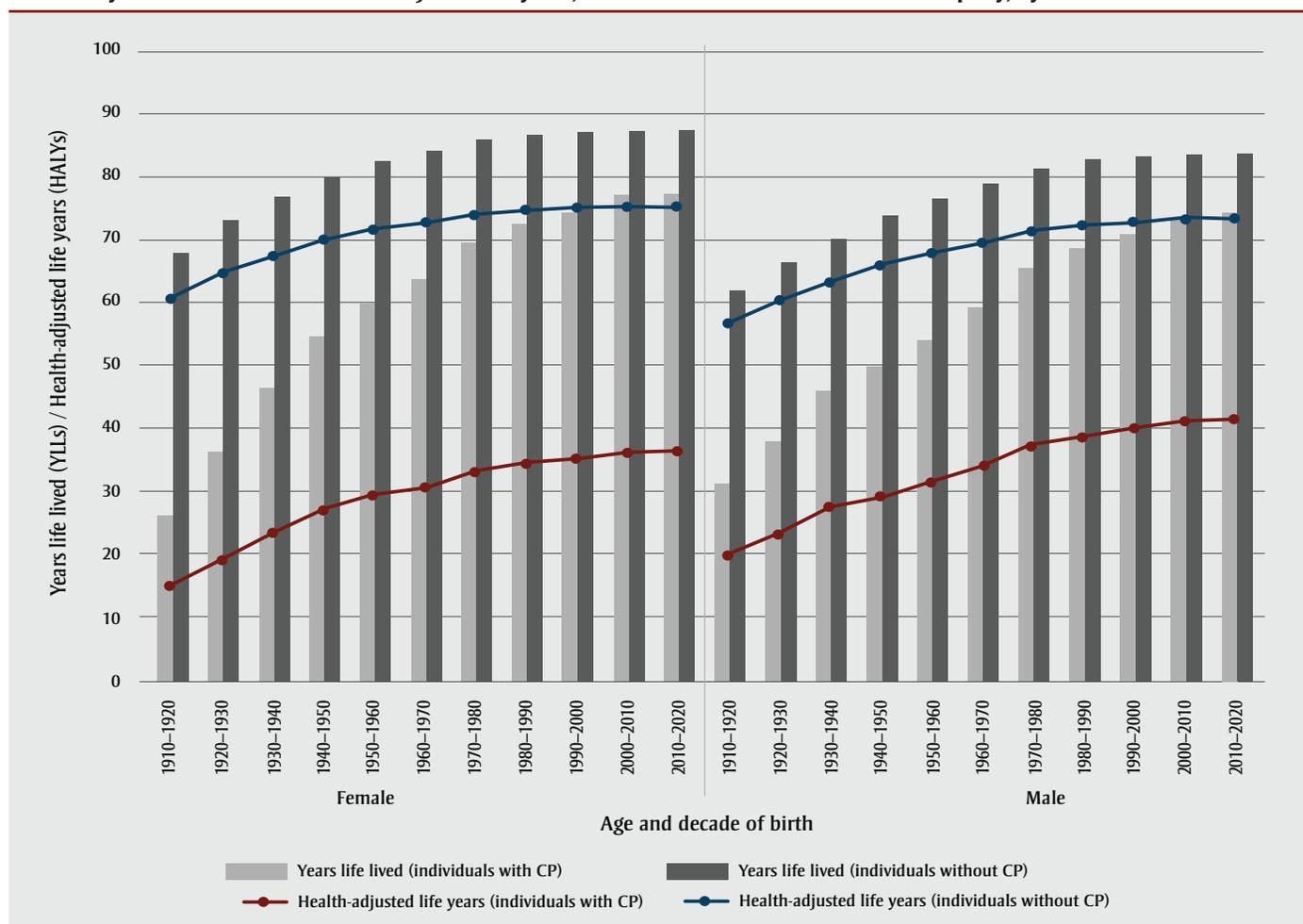er capita total health sector costs for Canadians with cerebral palsy and those who do not have a neurological condition.

The comparison shows that the greatest differences in costs occur prior to age 15 years. Around age 20 years, the cost differences begin to decrease (a ratio of 14:1) considerably and level off as people continue to age. By age 30 years, the ratio of total health care costs falls to 7:1. The model projects that the total mean per capita total health care costs will remain stable over the 20-year projection period because no change in costs per year was assumed.

The impact of living with cerebral palsy was also assessed by comparing the out-of-pocket expenses incurred by informal caregivers of Canadians with cerebral palsy and of those without a neurological condition. The difference was highest for informal caregivers of individuals aged under 35 years, with out-of-pocket expenses almost 50 times greater for caregivers of individuals with cerebral palsy than for those caring for individuals without a neurological condition (see Figure 8). A 36-fold difference is seen for informal caregivers of individuals aged 35–65 years. After age 65 years, the differences in out-of-pocket expenses are not as substantial.

As with other POHEM–Neurological parameters, the out-of-pocket expenses trend in 2011 is not expected to change by 2031 due to the status quo assumptions used during the modelling process.

Figure 9 also shows that total health sector costs associated with living with cerebral palsy will rise consistently over the next 20 years while the cost of care not related to cerebral palsy will remain stable over the same period.

Discussion

POHEM–Neurological projects the epidemiological and economic impacts of cerebral palsy over a 20-year period. Although the age- and sex-specific incidence of cerebral palsy was assumed to be constant over the projection period, the model projects an increase in the number of Canadians with cerebral palsy, from more than 75 000 in 2011 to more than 94 000 by 2031. As cerebral palsy is a chronic medical condition, more long-term supportive care services may be required to deal with the increase in the number of people with the condition.

In addition, POHEM–Neurological reflects the fact that people with cerebral palsy tend to have longer periods in poorer health-related quality of life (as reflected by lower scores on the HUI3) than their counterparts who do not have the condition. Although the core feature of cerebral palsy is nonprogressive motor impairment, cognitive impairment, feeding difficulties,

TABLE 2
Projected mean per capita total health care sector costs,[a] Canadian population with and without the condition, both sexes, by age, 2011 and 2031

Age group, years	Total health care costs, $				Ratio of cerebral palsy to nonneurological health care costs
	With cerebral palsy		Without a neurological condition		
	2011	2031	2011	2031	
< 1	30 497	30 353	1 900	1 899	16:1
1–4	11 666	11 671	564	564	21:1
5–9	10 129	10 140	484	484	21:1
10–14	10 108	10 149	463	463	22:1
15–19	9 765	9 771	702	701	14:1
20–24	8 471	8 489	854	851	10:1
25–29	7 615	7 607	1 066	1 068	7:1
30–34	8 599	8 580	1 215	1 227	7:1
35–39	7 203	7 185	1 216	1 225	6:1
40–44	8 678	8 654	1 305	1 308	7:1
45–49	9 322	9 324	1 575	1 574	6:1
50–54	10 915	10 903	1 998	1 996	5:1
55–59	13 868	13 983	2 514	2 513	6:1
60–64	14 158	14 151	3 204	3 207	4:1
65–69	17 248	17 263	4 129	4 132	4:1
70–74	20 498	20 516	5 168	5 174	4:1
75–79	19 302	19 371	6 343	6 348	3:1
80–84	21 344	21 343	7 546	7 550	3:1
≥ 85	23 555	24 141	9 197	9 177	3:1

[a] Total health care costs include physician, acute and rehabilitation hospital, prescription medication, provincial home care, assistive devices, long-term care and out-of-pocket expenditures for informal care by individuals with the condition and family/friend caregivers. Costs were estimated in 2010 constant (no inflation or discounting) Canadian dollars.

FIGURE 8
Average (per capita) out-of-pocket expenses incurred by informal caregivers, for individuals with and without cerebral palsy, by selected age group, 2011
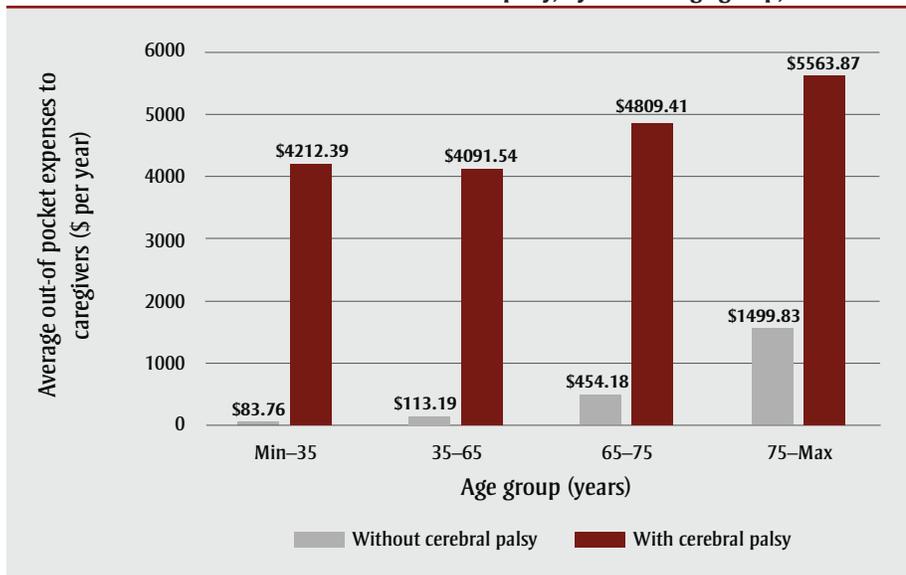


Abbreviations: Max, maximum age; Min, minimum age.

seizure activity, vision and mobility impairment are commonly associated conditions that may progress over time. Our study found that women living with cerebral palsy lose, on average, about 41 years of life in good health compared with Canadian women who do not have the condition: this value was about 33 years for men. The difference in HALYs between men and women is largely due to

differences in life expectancy as women live longer in poorer health (see Figure 7).

Long periods living in poor health and functional disability can result in an increased burden on the affected individuals and their families as well as on the health care system.

Total health care costs in all categories for Canadians with cerebral palsy will rise by
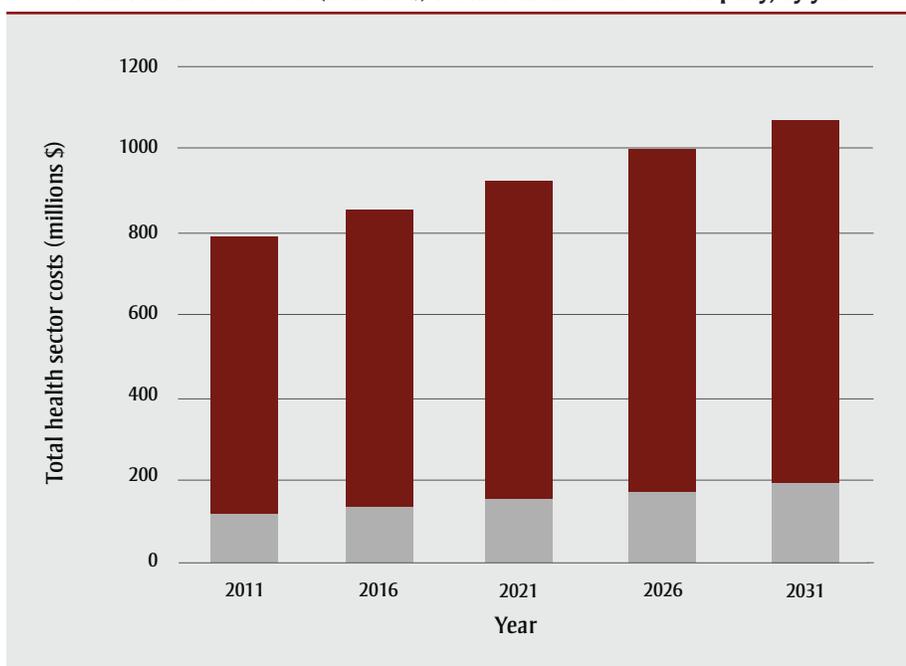
approximately 33% compared to less than 1% for costs not related to cerebral palsy. In addition, people with cerebral palsy and their families are expected to incur substantial out-of-pocket costs. As medical care and treatments advance, an increasing number of children with cerebral palsy are reaching adulthood. However, the provision of health care services and specialized programs tends not to keep pace with the needs of families and individuals, thereby making the transition from childhood into adulthood a challenge.[14,48,49]

As people with cerebral palsy experience a loss or reduction in the provision of health care services when they transition to adulthood, their demand for informal caregiving increases, and parents and relatives often step in to provide financial support and the required care. As noted in our study, the hours provided of informal care per week and out-of-pocket expenses incurred by the caregivers of people with cerebral palsy are substantially higher than those incurred by the relatives or friends of those who do not have the condition. The economic impact in terms of loss of income for informal caregivers is also an issue that requires more attention over the next 20 years as the impact of this condition is assessed.

Strengths and limitations

Our study offers important insights that strengthen our understanding of a complex neurological condition. POHEM–Neurological projections can help in the planning of future health programs and strategies for Canadians living with cerebral palsy.

The present findings from POHEM–Neurological assumed no future change in age- and sex-specific cerebral palsy incidence, relative mortality or functional health (HUI3). As such, the primary drivers of future prevalence, impact and cost of cerebral palsy derived from POHEM–Neurological are based on projected demographic shifts of the Canadian population. However, future iterations of the model could evaluate alternate scenarios, such as cost discounting, or variations in incidence or relative mortality, for their impact on the future of cerebral palsy in Canada.

Although incidence, mortality and costs were derived from Canadian provincial administrative data, the case definition

FIGURE 9
Total health sector costs (millions $) for individuals with cerebral palsy, by year

algorithm for identifying individuals with cerebral palsy had not been validated at the time of implementation. In initial assessments, model-projected prevalence rates were notably higher than observed rates. Therefore, a parameter was included in POHEM–Neurological that would, for a subset of actors, remove the designation of cerebral palsy from some prevalent cases. Such a parameter accounts for potential misdiagnosis, which is known to occur—hence the term "masqueraders of cerebral palsy."[38] A recent Canadian study compared an administrative data-based definition of cerebral palsy to a registry-based approach and found that 41% of cases administratively identified were not in the registry and that the former also missed 34% of registry-captured cases.[28] Therefore, a more sensitive definition of cerebral palsy may be needed if administrative data are to be used to capture incidence and costs associated with this condition. Alternatively, a combination of methods that included combining ICD codes and cerebral palsy diagnoses written in medical or educational records, as described in a 2019 study,[50] can be further analyzed to reduce errors in identifying cerebral palsy cases.

Limitations of POHEM–Neurological microsimulation models are expansively discussed in studies by Finès et al.,[30] Manuel et al.,[31] Amankwah et al.[32] and Hennessy et al.[51] Limitations such as applying incidence and mortality data obtained from one province to the entire nation, health care costs from two provinces, type I and II model error uncertainties and adjustments made to reduce the effects of the limitations are addressed in these studies.

Conclusion

Our study findings suggest that Canadians with cerebral palsy will continue to experience reduced quality of life, increased disabilities and a rising need for supportive services, including informal care. Health care expenditures, particularly out-of-pocket expenses, are projected to remain high over the next 20-year period. As people with cerebral palsy tend to have a normal life expectancy, they face continuous challenges related to an ongoing need for specialized medical care, accommodated education services, developmental assistance and general assisted living support. In addition, the indirect costs of lost productivity and wages to individuals and society, as well as occupational limitations, needs to addressed. More attention may be required for the transitional needs of people living with cerebral palsy as they pass through the different stages of life in situations where appropriate health care services and programs are inadequate or lacking.

Conflicts of interest

MO is a site investigator for clinical trials in spinal muscular atrophy by Roche, Biogen and Cytokinetics, and a past member of the data safety monitoring board for Avexis.

Authors' contributions and statement

NA, MO and RG contributed to the concept, drafting, analysis interpretation and critical review of the article. MO provided specialized content expertise on cerebral palsy, while RG, CB, DGM, RW, PF, JB, KT and KR contributed to data acquisition, microsimulation modelling and review of the article.

The opinions, results and conclusions reported in this paper are those of the authors, do not necessarily reflect those of the Government of Canada, and are independent from the funding sources. No endorsement by Institute for Clinical Evaluative Sciences or the Ontario MOHLTC is intended or should be inferred. Parts of this material are based on data and information compiled and provided by the Canadian Institute for Health Information. However, the analyses, conclusions, opinions and statements expressed herein are those of the authors, and not necessarily those of the Canadian Institute for Health Information.

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Original mixed methods research

Mandatory HIV screening, migration and HIV stigma in Canada: exploring the experiences of sub-Saharan African immigrants living with HIV in western Canada

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Abstract

Introduction: In this mixed-methods pilot study, we examined the intersections of the current Canadian immigration policy, mandatory HIV screening during the Immigration Medical Exam (IME) and enacted and internalized stigma for HIV-positive immigrants from sub-Saharan Africa (SSA) in a western Canadian province. We focus on qualitative findings from this study.

Methods: Using the Internalized HIV Stigma Scale (IHSS), we collected data from eight immigrants from SSA living with HIV in a western Canadian province. We then conducted semistructured interviews with seven of the eight participants. Due to the small sample size, survey data were summarized using descriptive analysis. Qualitative data were analyzed through constant comparative analysis.

Results: The following key themes emerged from analysis of qualitative data: experiences of HIV-related emotional distress during the IME; varied experiences of HIV testing during the IME; and inconsistent patterns of linkage to medical care, psychosocial supports and engagement in the HIV care cascade.

Conclusion: Findings from this pilot study cannot be generalized to the broader population of immigrants living with HIV in Canada. However, we found that the experiences of internalized HIV stigma and enacted stigma during the IME potentially influence the long-term engagement in the HIV care cascade during the process of migration and settlement in Canada. Further study in this population is recommended to examine the intersections of current mandatory HIV screening process during the Canadian immigration process, migration, settlement, culture, stigma and engagement in the HIV care cascade.

Keywords: HIV/AIDS, immigrants, sub-Saharan Africa, Canada, migration, immigration, HIV care cascade, Immigration Medical Exam

Highlights

- People from HIV-endemic countries, including most sub-Saharan African countries, are overrepresented in national HIV surveillance data in Canada.
- This pilot study contributes new knowledge about the experiences of sub-Saharan African immigrants living with HIV in one western Canadian province.
- This study provides new insights on intersections of culture, social determinants, HIV, stigma and potential impacts on the HIV care cascade and mental wellness during migration to and settlement in Canada.
- Further research is needed, including intervention research, to reduce stigma within the Canadian Immigration Medical Examination (IME) process and ensure better engagement in the HIV care cascade should be explored.

Introduction

Approximately 63 110 people are living with HIV in Canada.[1,2] Despite that people from HIV-endemic countries, including most sub-Saharan African (SSA) countries, are overrepresented in national HIV

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surveillance data,[1,2] very little is known about the experiences of SSA immigrants living with HIV in Canada. Although several population-based studies have been conducted in central Canada, information about SSA immigrants living with HIV in western Canada is limited, despite an increasing number of new cases of HIV among immigrants from countries where HIV is endemic.[3]

Most immigrants must complete an immigration medical examination (IME) as part of the application process to immigrate to Canada. Mandatory HIV screening was introduced in 2002. All IMEs are conducted by panel physicians designated by the Canadian federal government. Panel physicians are practising physicians living in Canada or non-Canadian nationals living in other countries.[4]

In Goffman's seminal work,[5] stigma refers to the complex concept of deviance and societal perceptions of people perceived to differ from societal norms. HIV-related stigma has been conceptualized in different ways in the literature.[6] *Internalized stigma* is defined as "the acceptance among people living with HIV of negative beliefs and feelings associated with HIV about themselves."[6,p4] *Enacted stigma* is defined as "acts of discrimination, such as exclusion, or physical or emotional abuse towards an individual's real or perceived identity or membership to a stigmatized group."[7,p.1] Internalized HIV stigma is associated with poor HIV medication adherence, poor engagement in the HIV care cascade and poor health and social outcomes.[8-13]

The immigrant population in Canada may face extraordinary barriers to achieving positive health and social outcomes compared to the non-immigrant Canadian population,[14,15] resulting in health inequalities. It is especially important to understand internalized HIV stigma among immigrants living with HIV, as immigration policies, migration and settlement experiences may affect their engagement in the HIV care cascade. Very little research exists on immigration applicants' experiences during the IME, HIV stigma, migration, settlement and access to specialized health services for HIV. More specifically, there is limited research on experiences of stigma during the IME's mandatory HIV screening. Also limited is research on how that stigma influences engagement in the HIV care cascade during migration to and settlement in Canada.

Objectives

Our research question was: How do SSA immigrants living with HIV in a western Canadian province internalize and experience HIV-related stigma encountered during the IME?

The objectives of this exploratory pilot study were (1) to measure HIV-related stigma among SSA immigrants living with HIV, using the Internalized HIV Stigma Scale (IHSS)[16]; and (2) to explore how SSA immigrants living with HIV experienced HIV-related stigma during the IME.

We examine our study results through the theoretical lens of intersectionality[17] and critical social theory.[18] We gathered insights on how mandatory HIV screening of immigration applicants, their legal status, stigma and culture influence health and social disparities in this population.

Methods

In this mixed-method pilot study, we collected quantitative data including sociodemographic and clinical data as well as data from the IHSS.[16] Qualitative data were collected through semistructured interviews. Using purposive sampling, we collaborated with community-based organizations and HIV clinics to recruit participants. Given the exploratory nature of this study, we were not aiming for a sample size with adequate power to detect statistically significant differences.

We used the following inclusion criteria: 18 years of age or older; a confirmed positive diagnosis of HIV; completion of mandatory HIV screening as part of the Canadian IME (this applies to immigrants who arrived in Canada after 2002); and ability to understand and speak English. Each interview lasted approximately one hour. An honorarium of $25.00 was provided. Offering this small honorarium (66% over the minimum hourly wage in this province) honours the expertise that community members bring, particularly experiential people, and shows the value of people engaged in community-based research.

Ethics approval was obtained from three university-based research ethics boards: University of Calgary (REB15–0471), University of Alberta (PR000056579) and the University of Lethbridge (HSRC2015–035).

The IHSS is the first documented multidimensional measure of internalized HIV-related stigma related to treatment and other aspects of the disease among sociodemographically diverse people living with HIV in North America. It is a 28-item measure of internalized HIV stigma composed of four subscales (stereotypes, disclosure of HIV concerns, social relationships and self-acceptance).[16]

Because of the small sample size in this pilot study ($N = 8$), we retained quantitative data for descriptive analysis only. The qualitative component of this study yielded rich data and is the focus of the findings reported here.

Members of the research team interviewed study participants using a semistructured interview guide. The interview guide included questions on HIV stigma; HIV testing during the immigration process; the experience of stigma; and engagement in the HIV care cascade during the IME, migration and settlement. Interviews were audiorecorded and transcribed verbatim.

We analyzed the qualitative data using approaches described by Corbin and Strauss.[20] Although we did not base this study on a grounded theory research method, the research team analyzed qualitative data in an iterative process of data analysis and data collection. Concepts related to HIV stigma were identified by the researchers working as a team. The concepts were grouped together under broader categories related to HIV stigma and the Canadian (IME) process, and then assessed, through constant comparative analysis, for patterns or themes of similarities and/or differences.[19,20] The research team engaged primarily in open coding[19,20] in analyzing data, with a primary focus on examining events, actions and interactions.

Results

Sample characteristics

HIV in the SSA immigrant community in Canada is a highly stigmatized and sensitive subject,[21,22] and the research team anticipated and experienced challenges in recruiting participants from the community. Working with community stakeholders and collaborators, such as HIV clinics and AIDS service organizations, and as a

result of multiple efforts, we were able to recruit eight participants who completed the IHSS survey; seven consented to an in-depth individual follow-up interview with a researcher. The legal status of participants varied: some were living in Canada as refugee claimants, some as government-assisted refugees and some as permanent residents under sponsorship*.

Table 1 summarizes the key characteristics of participants.

Due to the small sample size (N = 8), quantitative findings were descriptively analyzed to provide contextual information alongside the qualitative findings. Table 2 shows the number of participants who experience stigma "most" or "all of the time" in each IHSS domain. We found that most participants (5/8) had high internalized stigma associated with their positive HIV status in the domain of self-acceptance.

The Immigration Medical Examination process experience of immigrants living with HIV

The following key thematic categories emerged from our qualitative analysis of interview data:

- experiences of HIV-related emotional distress during the IME;
- varied experiences of HIV testing during the IME;
- inconsistent patterns of linkage to medical care, psychosocial supports; and
- engagement in the HIV care cascade.

Experiences of HIV-related emotional distress during the IME

Some of the participants, particularly those who were refugee claimants at the time of the interview, expressed significant worry and fear that their HIV status would jeopardize their ability to migrate to or legally remain in Canada. One participant noted that many of his fellow expatriates had gained permanent residency and had even become Canadian citizens, while he had been waiting for a long time. This individual believed his HIV-positive status contributed to the delays of his immigration application process:

I say this HIV brought my trouble, yeah, I was always living positive but when I see, like HIV has affected my being a Canadian permanent resident and a citizen, really that's when I get stressed... Maybe [my HIV] delay my immigration... (P100)

TABLE 1
Characteristics of study participants (N = 8)

Variables	Frequency, n
Sex	
Male	4
Female	4
Immigrated to Canada	
Before 2010	1
In 2010–2014	5
After 2014	2
Annual income, $	
< 10 000	2
10 000–25 000	3
25 000–40 000	2
> 40 000	1
Education completed, years	
5–8	1
9–10	0
11–13	2
≥ 14	5
Relationship status	
In a relationship with one person	4
Not in a relationship	4
Sexual behaviour	
I am a man who has sex with women	4
I am a woman who has sex with men	3
Other	1
HIV test was done during Canadian IME	
Yes	8
Found out for the first time about HIV-positive status at Canadian IME	
Yes	3
No	5
Diagnosed with AIDS	
Yes	5
No	3
Taking medication for HIV	
Yes	8
Knowledge about the last CD4 count	
Yes	3
No	3
Missing	2

Abbreviation: IME, Immigration Medical Exam.

* Refugee claimants may apply to immigrate to Canada via private sponsorship. The sponsor is typically a group of Canadian citizens willing to sponsor and support the refugee applicant during the application and settlement process, as per current policy (https://www.canada.ca/en/immigration-refugees-citizenship/corporate/publications-manuals/guide-private-sponsorship-refugees -program.html).

TABLE 2
Number of participants reporting internalized HIV stigma experienced "most" or "all of the time" for each IHSS domain (*N* = 8)

Domain	*n*
Stereotype	3
Disclosure concern	2
Social relationships	1
Self-acceptance	5

Source: Sayles et al.[16]
Abbreviations: IHSS, Internalized HIV Stigma Scale.

On being positively diagnosed for the first time during the IME, one participant described worrying about the effect on his family and the immigration process for himself and his children:

> ...Everything gone, all the happiness, the excitement, the hope I had to come to Canada, it's all gone at once...when the doctor told me my results, you are HIV positive, but your HIV does not affect your immigration process... I felt it might affect me, I still didn't believe [the immigration doctor]... that's why I had the feeling... not only for me but for my family, for my kids... that is like [a] penalty for my kids... [I was] very much worried...(P104)

Another participant described worrying about his children after learning of his positive diagnosis:

> I think in my life I have never been so stressed. This is the first time of knowing what stress is... I have a family, my children...at the same time they are suffering because of [this HIV]... (P100)

One participant was scared that his sponsor hosts would no longer want to support his immigration once they found out that he was HIV positive:

> … the Canadian government, they have the responsibility of protecting Canadian citizens. So [the IME physician] say[s] that I have to tell my host that... situation and it was up to [the sponsor host] to decide if he wanted me to come anyway or that he didn't want to. I was scared... I don't know what is going to happen. I don't know if I'm going to be sick, I don't know if [the host] is going to want me [and my child] to stay [with them]... (P107)

One participant described the jarring dissonance of the news of being accepted as an immigrant to Canada while learning of his positive HIV diagnosis:

> …when [the immigration doctor] told me that I was HIV positive … I couldn't talk to her, I was shaking, you know like that shaking, I was so angry. You know everything gone … to get that visa to come to Canada was... it's something special you know for Africans, for us, […]. I waited for 10-something years, you know, to get out … After I was told my [HIV] results... I did not have any interest to look at anything. My wife was asking why [I] don't look happy [asking]... what's wrong with you? (P104)

Three participants spoke of the trauma of receiving a positive diagnosis for HIV for the first time during their IME. Some ideated suicide after learning of their diagnosis:

> I was just asking … how I can kill myself? That's what I was thinking. Yeah. I think there was some time it came in my mind. That's what I was thinking. I'm alone. I'm just lonely... I was crying because I was just in the room and I'm so lonely... sometimes I was trying... I can kill myself. (P106)

Another participant described their despair upon first learning of their positive diagnosis:

> … Like feeling that I'm not worth living, maybe I should die... I really got stressed and I had never been stressed... (P100)

Varied experiences of HIV testing during the IME

Participants were asked to describe the HIV testing during the IME. Participants discussed the extent to which they gave informed consent for HIV screening. Four of the participants were not told that the IME would include a mandatory HIV test. Participants stated that neither pre-HIV test counselling services nor information about the IME process were provided. Participants described feeling desperate to leave their countries and being willing to fulfill any medical requirements, without questioning what was being asked of them.

Five participants knew of their HIV status prior to the IME. One of the participants who first learned they were HIV-positive through the IME process described the news as devastating:

> I went to see the doctor with my family and my wife and my kids … and then finally [the immigration doctor] let my kids and my wife out but she asked me to stay, and when we were alone she told me that I was HIV positive … all the happiness, the excitement, the hope I had to come to Canada, it's all gone at once in that one minute. (P104)

Participants' interactions with the panel physicians differed based on whether the IME took place in Canada or overseas. Of the seven participants who agreed to be interviewed, three underwent the IME in Canada whereas four had the examination prior to coming to Canada (in Botswana, Sudan, Uganda and Zimbabwe). Most of the participants who completed their IME in Canada felt the panel physician and associated health professionals provided compassionate, empathetic and respectful care. In contrast, participants who completed their IME overseas identified more concerns and problems to do with privacy and confidentiality, as well as the feeling of being judged by the IME physician. One participant noted:

> The problem was the way you get your results. They are not really... comfortable in telling you. (P102)

One participant who completed the IME in Botswana felt significantly judged:

> …the one who was doing my test was like, he is scared of me. You know, I was like a dirty person. I was … like you're a dead person. (P106)

Participants received varying types of counselling after learning of their positive HIV diagnosis. One participant was so shocked to hear they were HIV positive, they could not clearly recall the counselling they received:

They tell me [HIV] is part of life... just take it easy...and then myself, my mind was not there... my first time to hear about [my HIV diagnosis]. I was like I'm crazy. I didn't hear what [the immigration doctor] was talking about... I didn't even hear. (P106)

Inconsistent patterns of linkage to medical care, psychosocial supports and engagement in the HIV care cascade

Participants reported a wide variety of follow-up referrals and linkage to care and supports following the IME HIV testing process. In addition, participants received inconsistent counselling on how to manage their HIV in Canada and disclosure of their HIV-positive status to others.

Only one participant described being told by the IME panel physician about how the health care system worked and how their HIV care should continue once they arrived in Canada:

The [immigration doctor explained] the system in Canada... once they know you are HIV positive, they contact you as soon as possible so that they start taking care of you... they open your file, they make sure they get you HIV specialist, a family doctor... all of those things they told me. (P101)

One participant knew her HIV-positive status and was on treatment at the time of her IME. After she told the panel physician about this, the physician neither enquired about her level of engagement in the HIV care cascade nor advised her about Canadian laws regarding HIV nondisclosure. The participant noted that the panel physician in her home country provided only a short-term prescription of HIV medications and offered no advice about how to continue treatment once she arrived in Canada:

... Yeah I got medicine for two months so that I could at least take it while waiting to see, to wait for the doctor here in Canada... That's the only thing they gave me. (P105)

Another participant also reported that the panel physician did not tell her about the health care system in Canada, the laws pertaining to HIV nondisclosure or how to access HIV care in Canada. Her aunt in Canada was the one who facilitated her linkage to specialized HIV care:

When I came, my aunt knew about my situation, so she's the one who actually [...] sought [out] this clinic and talked to them and she told them, 'Oh, I've got my cousin. She is new to this country and she needs help in this and that and that.' That's how I got to know to go there, yes, it was only through my aunt, yes. (P102)

Several participants did receive advice about disclosure of their HIV-positive status to their partners. Only one participant described being given specific advice about HIV nondisclosure laws in Canada:

The [immigration] doctor told me if I have someone I must tell everything about myself [including about the HIV status]... It is difficult for me to say... [so] I just keep to myself. (P106)

Five participants reported that they did not begin HIV treatment until they had arrived in Canada. One participant was told by the diagnosing panel physician in Botswana that he was "still okay" because his "CD4 count was above 200." A participant whose CD4 count was above 200 reported that he was not eligible to access affordable antiretroviral therapy (ART) in Uganda. A friend reassured this participant that HIV treatment would be provided free of charge in Canada:

This is a country where they have very nice treatment and it will be given to you free, so don't get worried of anything. You will be taken care of. (P100)

Discussion

Findings from this pilot study reveal important insights into the experiences of SSA immigration applicants living with HIV in a western Canadian province. These findings speak to the intersections between current Canadian immigration policy, including mandatory HIV screening during the IME; adequate and appropriate pre- and post-HIV-test counselling, including engagement with the HIV care cascade; HIV-related stigma, including internalized HIV stigma among immigration applicants and enacted stigma in the immigration system; and disparities in HIV care cascade engagement.

Most immigration applicants who wish to migrate to and settle in Canada must complete an IME conducted by a registered panel physician in Canada or overseas.

The IME involves screening and assessment of physical and mental health; HIV screening is mandatory. The "regulated exceptionalism in the form of mandatory immigration HIV testing policy"[23,p.128] during the IME and the ethical implications of such a public policy have been discussed elsewhere.[23,24] HIV testing as part of the IME became mandatory in 2002; it remains the only test added to the IME in the past 50 years.[23,24] HIV screening in the context of the IME is done to mitigate risk to the public health of Canadians and the demand on the Canadian health and social care systems. According to the *Immigration and Refugee Protection Act*,[25] an immigration applicant may be not admitted to Canada if they are deemed to be a potential risk to the public health and safety of Canadians or a potential burden on the Canadian health care system.

At times, the test confirms prior knowledge of an HIV diagnosis; at other times, it is the first diagnosis for immigrants, refugees and/or temporary foreign workers. It is important to consider the consequences of HIV screening among immigration applicants, particularly those who are vulnerable (e.g. refugees) or at significant risk of harm if returned to their countries of origin due to their positive HIV status. Many people living with HIV in SSA countries experience multiple vulnerabilities, including reliving past trauma,[21,26] or have no access to HIV treatment.[21,26]

Although the stated primary purpose of mandatory HIV screening during the IME is to determine public health risk or excessive demand on the health system, Canada needs to consider the human rights implication of conducting mandatory HIV screening during the immigration process. Though some immigration applicants (for example, family class or refugee applicants) who test positive for HIV may not be assessed as medically inadmissible,[27] others may be.

The IME panel physician should refer all applicants who test positive for HIV during the IME process to appropriate treatment and care. In our study, not all participants described appropriate care measures during the HIV testing process. They described genuine fear about their HIV-positive status and the impact that a positive diagnosis may have on their immigration application. This fear of living with HIV or starting ART resulted in

significant emotional distress at the time of diagnosis, with some participants ideating suicide. Participants reported lack of emotional support immediately after receiving their positive HIV diagnosis.

Finally, several participants reported delaying HIV treatment. While HIV treatment guidelines and initiation of ART are complex,[28] those participating in this study did not describe having in-depth discussions on HIV treatment and support options with the IME panel physician.

The Government of Canada provides panel physicians with information about key policies and procedures related to the IME, including mandatory HIV screening.[4] The Public Health Agency of Canada outlines components of appropriate pre- and post-HIV test counselling.[4,27,29] While guidelines are provided for age- and gender appropriate and culturally sensitive counselling prior to and after HIV testing, participants reported different experiences of counselling during the HIV testing portion of the IME. Further, based on current available information, we cannot determine the level of training provided for registered panel physicians to conduct the IME in Canada and overseas.

Adequate and appropriate counselling pre- and post HIV testing is critical to promote positive health and social outcomes for people living with HIV as well as for people at risk for acquiring HIV.[30,31] Further, adequate counselling has been described as the gateway to the HIV care cascade, in which people are aware of and make informed choices with respect to HIV testing, diagnosis, medical treatment and ongoing care and support.[30,31]

Pre-HIV test counselling is not time consuming.[31] It includes telling the individual about their rights regarding HIV screening and about the process, potential outcomes and follow-up care and support. As much as possible, counselling should be in the immigration applicant's language. Current standards for pre-HIV test counselling include, at a minimum, a conversation with the patient regarding means of HIV transmission and prevention; a description of the testing procedure and confidentiality, reporting and record handling; meaning of HIV screening test results, including the possibility of false positive or false negative results; the need to inform anyone at risk of infection if the

test is positive; and the need for the patient's consent to undergo testing.

Our findings suggest that participants may not have received adequate or appropriate pre-HIV test counselling. Also significant is that more than half of the participants reported not being informed that an HIV test was a mandatory part of the IME. From a human rights-based approach to public health, individuals must be informed and be able to provide consent to HIV testing.[31]

Current Canadian IME guidelines indicate that post-HIV-test counselling is not mandatory for immigration applicants who test negative for HIV[31] but is required for those who test positive. The post-HIV-test counselling should include referral to an HIV specialist for counselling, HIV viral load testing, CD4 counts and ART, when indicated.[27,31] Further, panel physicians are required to complete a form that immigration applicants sign, acknowledging completion of post-HIV-test counselling.[27,31] Several participants in our study did not receive adequate post-HIV-test counselling. For example, one participant reported not being told how to seek HIV treatment after the IME process or on arriving in Canada. This participant relied on relatives in Canada to access HIV specialized care. None of the interviewees recalled signing the form that acknowledged receipt of post-HIV-test counselling. This exposes a troublesome disconnection between the IME process and linkage to HIV care and support, particularly given Canada's stated policy commitments to the UNAIDS 90–90–90 treatment target to help end the global AIDS epidemic.[32]

People living with HIV in Canada need to be informed of the medicolegal implications of HIV transmission without disclosure.[33] The criminalization of HIV nondisclosure is a complex issue.[33] The Supreme Court of Canada "has ruled that people living with HIV have an obligation to disclose their status to a sexual partner before sexual activity that poses a significant risk of serious bodily harm"[33,p.3,34]. In the face of complexity regarding HIV nondisclosure laws in Canada, our study findings show that participants received minimal information about their legal obligation to disclose their HIV status to a sexual partner. In addition, participants reported receiving this information about their legal obligation in varying degrees of

detail. This too is of concern from a rights-based perspective. If people living with HIV are not aware of the laws of the country into which they are settling, they may be at risk for becoming entangled with the Canadian legal system.

The role of the panel physician during the IME has been previously questioned.[23,24] We propose that the IME panel physician play a key role in engaging immigration applicants in the HIV care cascade during the premigration and migration process; provide information on how the immigration applicants could remain engaged in the HIV care cascade once in Canada; and inform the HIV-positive immigration applicant about the medicolegal implications of HIV nondisclosure.

Instead of being limited to HIV detection for the purpose of immigration policies, the panel physician could act as an important catalyst to ensure immigration applicants engage in the HIV care cascade during their migration to and settlement in Canada. The IME panel physician could also make sure that the individual understands the options for HIV care and support during the migration and settlement trajectory. Based on our findings, it was not clear how participants engaged or continued to engage in their HIV care from the time of their diagnosis to the referral to an HIV specialist.

The IHSS data reveal that study participants' experiences contributed significantly to internalized stigma associated with self-acceptance. Examining IHSS data alongside participants' shared experiences raises questions on the relationship between internalized HIV stigma and institutional structures such as policy, clinical practice guidelines for mandatory HIV screening during immigration, health care provider practices and people's social contexts of migration and settlement.

Participants also described a layered effect of internalized HIV stigma and emotional stress: stress related to transnational migration and settlement, that is, the immigration process, and stress associated with receiving a new HIV diagnosis or managing their HIV-related illness during migration to Canada. The emotional distress experienced by participants who receive a positive HIV diagnosis for the first time during the IME was significant. People have reported feeling trauma after

receiving a positive HIV diagnosis, and responses to such a diagnosis include shock, disbelief, depression, suicide ideation and anger.[35-38]

Participants described worrying and feeling stressed about how their positive HIV diagnosis would negatively affect their immigration application to Canada. Although refugee applicants cannot be denied admissibility based solely on a positive HIV diagnosis, internalized stigma was evident through the intense fear of deportation several applicants described.

Immigrants comprise a significant segment of Canadian society. It is important that Canada, as host country, ensures their health and social wellbeing, including those living with HIV. At approximately 20% of the total Canadian population, immigrants are vital in overall population growth in Canada; they also help address labour shortages, strengthen the national economy and contribute to demographic stability in the long term.[39,40] Our findings suggest that immigrants living with HIV may face barriers to achieving optimal health and social outcomes due to internalized HIV stigma, enacted stigma and potential disengagement with the HIV care cascade during the process of migration and settlement. Health and social inequalities in this population may preclude individuals from participating fully and meaningfully in Canadian society.

Within the institutional structures of the IME, several participants reported enacted stigma. Our findings revealed missed opportunities during the physician–patient interaction to engage people in the HIV care cascade in nonjudgmental ways. Some participants reported receiving caring interaction with the IME physician, while others did not. Although IME panel physicians are general practitioners and not necessarily infectious disease specialists, they are a critical point of contact for Canadian immigration applicants. By proxy, the IME panel physicians are a first point of contact to the Canadian health and social system; they could play a key role in ensuring compassionate care during the IME and the engagement of HIV-positive immigration applicants in the HIV care cascade during premigration, migration and settlement.

Our findings indicate a need to further investigate the experiences of HIV-positive immigrants during the Canadian IME process in relation to their engagement in the HIV care cascade.

Strengths, limitations and opportunities

There are several limitations to this exploratory pilot study. First, the sample size was small ($N = 8$) and only included immigrants from SSA countries. Therefore, findings of this study cannot be generalized to other immigrant populations living with HIV in Canada.

Second, all participants were recruited from one western Canadian province. Further studies should include participants who migrate to and settle across Canada. Though health care is publicly funded across Canada, health care systems, including service delivery, access to HIV care and support for newcomers, vary among Canadian provinces and territories. These variations may influence the experiences of internalized HIV stigma and of the HIV care cascade among immigrants living with HIV.

Third, the authors were not able to conduct a gender-based analysis of pilot data to allow examination of patterns of stigma among men, women or people who identify as transgender due to the small sample size.

Despite these limitations, the findings of this study act as a catalyst to further investigate the experiences of immigration applicants during mandatory HIV screening, internalized and enacted stigma during the IME, and how systemic factors can potentially affect health and social inequalities in immigrants living with HIV in the context of migration to and settlement in Canada. By understanding such social processes, we can develop ways to better support improved health and social outcomes of migrants to Canada living with HIV.

Finally, it is important to attend to the psychosocial and mental health needs of all people, including immigrants, living with HIV. Our findings show the critical importance of supporting the wellbeing of SSA immigrants living with HIV in Canada. Many migrants experience significant trauma as a result of displacement, armed conflict, violence and human rights violations.[41] Our findings suggest that immigration applicants may require strengthened psychosocial support given the significant potential effects on mental health and wellbeing that the intersections of past trauma, living with HIV, class and culture can have. Further study is needed to understand the mental health and wellbeing of immigrants living with HIV across regions in Canada.

Conclusion

Results of this study indicate disparities in the way that mandatory HIV screening is conducted by government-registered IME panel physicians located in Canada and overseas. Despite standard HIV screening guidelines for panel physicians, participants reported a range of experiences. Key themes that emerged included HIV-related emotional distress and varied experiences of HIV testing during the IME and inconsistent patterns of linkage to medical care, psychosocial supports and engagement in the HIV care cascade. This warrants further study as immigration applicants' engagement in the HIV care cascade could be compromised by inconsistent HIV test counselling procedures and resultant HIV stigma.

This study contributes to the information on the experiences of SSA immigrants living with HIV in Canada, particularly in western Canada. Availability of HIV care, treatment and support varies across provinces and territories. It is important to understand the social context of immigrants living with HIV, and how this may influence engagement in the HIV care cascade. Further study in this population is recommended to examine the intersections of current mandatory HIV screening process during the immigration process, migration, settlement, culture, stigma and engagement in the HIV care cascade.

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Conflicts of interest

There are no financial or other conflict of interest. None of the authors benefited as a result of this study.

Authors' contributions and statement

This is a community-based research project and all the authors collaborated in the development, writing, review and finalization of this manuscript. Several authors took the lead for certain sections of the manuscript. ADC, VC, SP and JH created the outline of the manuscript and developed the ideas presented with ongoing engagement and dialogue with co-authors for input and feedback. ADC, VC, SP, JH, MH and AA took the lead in the data analysis and synthesis of findings, with ongoing engagement and dialogue with co-authors for input and feedback.

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Original quantitative research

Using the intervention ladder to examine policy influencer and general public support for potential tobacco control policies in Alberta and Quebec

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Abstract

Objective: To assess general public and policy influencer support for population-level tobacco control policies in two Canadian provinces.

Methods: We implemented the Chronic Disease Prevention Survey in 2016 to a census sample of policy influencers ($n = 302$) and a random sample of members of the public ($n = 2400$) in Alberta and Quebec, Canada. Survey respondents ranked their support for tobacco control policy options using a Likert-style scale, with aggregate responses presented as net favourable percentages. Levels of support were further analyzed by coding each policy option using the Nuffield Council on Bioethics intervention ladder framework, to assess its level of intrusiveness on personal autonomy.

Results: Policy influencers and the public considered the vast majority of tobacco control policy options as "extremely" or "very" favourable, although policy influencers in Alberta and Quebec differed on over half the policies, with stronger support in Quebec. Policy influencers and the public strongly supported more intrusive tobacco control policy options, despite anticipated effects on personal autonomy (i.e. for policies targeting children/youth and emerging tobacco products like electronic cigarettes). They indicated less support for fiscally based tobacco control policies (i.e. taxation), despite these policies being highly effective.

Conclusion: Overall, policy influencers and the general public strongly supported more restrictive tobacco control policies. This study further highlights policies where support among both population groups was unanimous (potential "quick wins" for health advocates). It also highlights areas where additional advocacy work is required to communicate the population-health benefit of tobacco control policies.

Keywords: health policy, tobacco control, public opinion, knowledge, attitudes and beliefs, Nuffield intervention ladder, survey research, population studies, Canada

Introduction

Despite Canada's Tobacco Strategy goal of less than 5% tobacco use by 2035,[1] the prevalence of current cigarette smoking has significantly increased, from 13% in 2015 to 15% in 2017.[2] The negative impacts of tobacco misuse are not felt equally across the country; they are connected to other health and social inequalities,[1] with higher rates of tobacco misuse found among sexual minorities, young adults and Indigenous peoples.[1] Comprehensive environmental and policy interventions are required to effect substantial population-level changes[3] and reduce inequities[4] in tobacco misuse. While improving access to cessation treatment options (e.g.

nicotine replacement therapy) has demonstrated some benefit at the individual level,[5] the impact of these health service programs pales in comparison to higher-order environmental and policy approaches.[6] For instance, it has been estimated that a tax increase of 50% on the current price of cigarettes (with no value-added tax) would reduce smoking prevalence by 18% over a 40-year period; evidence-based cessation treatments (e.g. pharmacotherapies) would only reduce smoking prevalence by 4% over the same period.[6]

Highlights

- Previous research has demonstrated that policy and environmental interventions are high-impact approaches to reducing smoking and tobacco consumption at the population level.
- Understanding the attitudes of policy influencers and members of the general public is essential, as their support can hinder or promote effective policy action.
- This study provides recent evidence on the attitudes of policy influencers and the public towards population-level tobacco control policies in two Canadian provinces.
- These findings will be useful for health advocates to identify policy areas where support is unanimous (i.e. potential "quick wins") as well as areas where support is weak or lacking consensus.

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The knowledge, attitudes and beliefs of policy influencers (e.g. elected, hired or otherwise appointed professionals with legal standing, authority or input on various policy processes in governments, schools boards, workplaces and the media)[7] and the general public play an important role in changing political agendas.[7] While policy influencers are considered the ultimate gatekeepers of policy action, those in elected positions are, in part, influenced by the opinions of their voters and can be particularly attuned to issues the public considers controversial.[8] While greater levels of public support for tobacco control have contributed to the success of legislative efforts,[9,10] Chen et al.[11] noted that lower levels of support have left policy makers vulnerable to tobacco industry interests.[12] Internationally, recent research has explored public support for specific types of tobacco control interventions (i.e. anti-smoking media campaigns[13] and pictorial warnings on cigarette packs[14] in the United States of America); and support for tobacco control policies among specific population groups (i.e. smokers in Canada,[15] adolescents in Hong Kong[11] and adults in the USA,[16] Finland[17] and Malaysia[18]).

Within the Canadian context, despite a limited number of studies examining the knowledge, attitudes and beliefs of policy influencers and the general public on specific initiatives,[7,19,20] there remains a paucity of evidence concurrently assessing both policy influencer and general public perspectives across a wide range of tobacco control policy options. Having current data on both policy influencer and general public perspectives is important, as previous research has demonstrated that health policy advisers tend to underestimate general public levels of support for tobacco control legislation.[21] Such misinterpretations may have impeded policy action.[21]

In 2009, the Alberta Policy Coalition for Cancer Prevention (later renamed as the Alberta Policy Coalition for Chronic Disease Prevention [APCCP]) developed the Chronic Disease Prevention (CDP) Survey to assess the knowledge, attitudes and beliefs of policy influencers and members of the general public on healthy public policy for chronic disease prevention in Canada. Since 2009, the survey has been administered six times to examine support for tobacco control policy, most recently in 2016. The survey provides data to support

public health advocates working to reduce the prevalence of this deadly behavioural risk factor.

The 2016 survey assessed the general public's and policy influencers' support for population-level policies to reduce tobacco-related harm in two Canadian provinces, one western and English-speaking (Alberta) and one eastern and French-speaking (Quebec). We also aimed to compare patterns of support between policy influencer and general public groups as well between regions. In our analysis of data from this sample, we used the Nuffield Council on Bioethics (NCB) intervention ladder as a framework to consider the balance between individual autonomy and collective benefit for each of the surveyed policy options.[22] Research on policy acceptance has demonstrated that the way policy/intervention affects individual freedom of choice is a strong predictor of policy/intervention acceptance.[23] In neoliberal countries such as Canada that lean towards individualistic rather than collective or communitarian values,[24] the autonomy versus collectivity debate is an important lens, potentially determining the levels of support for healthy public policy adoption. Further, by characterizing interventions as more or less restrictive to individual autonomy, the intervention ladder framework allows for comparison of differences and understanding of similarities in terms of the psychosocial mechanisms operating on population-level behaviour. Relevant literature that has employed the intervention ladder to propose and evaluate public health policies include research in the field of occupational health,[25] infectious diseases,[26] public health nutrition,[27-30] physical activity,[31] alcohol[32] and tobacco control.[33]

Given the renewal of Canada's tobacco control strategy,[1] our recent survey contributes timely evidence on attitudes towards tobacco control policy options in two provinces in Canada. Our findings illuminate trends in the type of tobacco-related policy interventions most likely to garner wide support and can thereby help to strategize priorities for future healthy public policy advocacy initiatives.

Methods

Chronic Disease Prevention Survey

The CDP Survey aims to understand the knowledge, attitudes and beliefs of policy

influencers and the general public on healthy public policy related to major modifiable risk factors.[34] The findings presented here focus on results from the 2016 CDP Survey, administered in English and French, assessing support for healthy public policy approaches specific to tobacco control in Alberta and Quebec. We also aimed to compare patterns of support between policy influencer and general public groups as well between regions. Survey respondents were asked to rank their support for tobacco control healthy public policy options on a four-point Likert-style scale measuring opposition versus support (1 = strongly oppose, 2 = oppose, 3 = support, 4 = strongly support). The evidence-based policy options to reduce tobacco use included in the survey were developed in collaboration with a team of experts from the APCCP with specialized knowledge and experience in tobacco control to ensure that the policy options aligned with existing national recommendations.

This study was approved by the Research Ethics Office at the University of Alberta (Pro00046150 and Pro00044424).

Survey respondents

A census sample of policy influencers were invited by email to participate in an online survey that included 29 items related to tobacco control policies. The census sample of policy influencers was developed using publicly available information (e.g. organizational websites that provided contact information such as the Legislative Assembly of Alberta and the National Assembly of Quebec, school board associations for each province, media directories in each province, the Orbis database of private companies to identify workplaces with more than 500 employees and by subsequently searching the relevant websites for chief executive officers, human resource executives and health and safety executives, etc.).

We used a comprehensive definition of "policy influencer" that focused on three core domains of influence: government actors at the municipal and provincial level due to their decision-making authority; non-governmental leaders within school and workplace settings due to the impact that policies in these key environments have on improving health outcomes;[35] and media actors due to their influencing role in shaping public opinion

and legislative agendas through policy narratives.[36] This comprehensive definition of "policy influencer" aligned with our research objective to provide an aggregate population-level view of policy influencers' perspectives across settings.

The policy influencer sampling frame included all elected provincial legislators in Alberta and Quebec; senior provincial bureaucrats at the deputy ministerial level; mayors, reeves and senior municipal bureaucrats; school board members and chairs; senior executives of companies with over 500 employees; and editors/health reporters for print media outlets.

Within our census sampling frame, 115 email contacts bounced back (33 in Alberta, 82 in Quebec), 61 substituted emails were included where we were advised to contact another person (20 in Alberta, 41 in Quebec) and 25 emails resulted in direct refusals (18 in Alberta, 7 in Quebec). Ethical information related to the voluntary nature of participation and confidentiality was outlined on the main page of the survey. Consent was implied when participants chose to continue on and complete the survey.

A shorter subset of the survey (13/29 policy options related to tobacco control) was administered to the public, who were sampled via random digit dialling (stratified by sex, urban versus rural residence and age, at the household level, to achieve a weighted sample proportionate to the Canadian population in those regions). Policy options included as part of the shorter subset of the survey were determined through expert consensus by members of the APCCP and the Policy Opportunity Windows—Engaging Research Uptake in Practice (POWER UP!) CLASP. The focus was on timeliness and relevance in the current tobacco control advocacy environment in each province, that is, were current or anticipated policy issues relative to decisions being made in each province at the time of the survey.

The general public survey was administered by a professional polling firm using computer-assisted telephone interviewing. We requested that the contracted survey vendor complete 2400 interviews with 400 participants each in Calgary, Edmonton, Montréal, Québec City, the rest of Alberta and the rest of Quebec. Eligible households that were "non-interviews" included

refusals, partial interviews, language barriers, underage respondents and answering machines. Potential participants were informed their participation was voluntary. Verbal consent was obtained to proceed with the telephone survey. None of the survey participants received any type of incentive to participate. Demographic data for both sample groups were also collected.

Analysis

Aggregate responses were analyzed for each tobacco control policy option by deriving the net favourable percentage (NFP)[37] for both public and policy influencer responses as well as by province. NFPs are calculated by subtracting the percentage of respondents who "strongly oppose" or "oppose" from the percentage of respondents who "somewhat support" or "support" a policy option. The resulting metric has a continuous range from $+100$ to -100 and is readily interpretable (positive percentages indicate favourability while negative percentages are considered unfavourable). To facilitate a consistent comparison of levels of support across the different tobacco control policy options and by sample group, we used Roselius'[37] seven categories for qualitative interpretation of NFP values (see Table 1). We opted to use this categorical framework to compare levels of support since NFP values are descriptive, rather than inferential, statistics.

In addition, all policy options were coded according to the different levels of the NCB intervention ladder in order to consider policies in terms of their benefits to society against any loss of individual autonomy.[22] The NCB intervention ladder proceeds along steps from least to most intrusive, including do nothing; provide information; enable choice; guide choice

through changing the default policy; guide choice through incentives; guide choice through disincentives; restrict choice; and eliminate choice.[22] Three coders categorized each tobacco control policy option in the CDP Survey using a detailed codebook.[38] Any disagreements were resolved by consensus and in consultation with the principal investigator.

During this coding process, we found that not all policy options fit into the existing levels of the NCB intervention ladder. Hence, we developed a separate category called "reorient government action." This new level accounted for policy options focused on interventions that implicated the way government takes action, rather than directly affecting individual autonomy (e.g. sue tobacco companies to seek compensation for those who have been harmed by tobacco products).

Results

The response rate for the 2016 CDP Survey was 5.1% of 5926 invited policy influencers ($n = 302$; $n = 174$ in Alberta and $n = 128$ in Quebec) and 7.4% of 32 580 invited members of the general public ($n = 2400$; $n = 1200$ in Alberta and $n = 1200$ in Quebec). Table 2 presents survey respondent demographics. While policy influencer respondents in our survey were more often older and male, this demographic profile reflects the makeup of policy leaders in Canada more generally.[39,40]

Similarly, general public respondents were selected at the household level to reflect the demographic profiles within their respective provinces.

Both policy influencers and the general public considered all of the policy options to be "slightly," "very" or "extremely favourable," with the exception of one

TABLE 1
Roselius' qualitative interpretation of favourability levels based on net favourable percentages[37]

Qualitative interpretation	Net favourable percentage range
Extremely favourable	+100 to +71.5
Very favourable	+71.4 to +42.9
Slightly favourable	+42.8 to +14.3
Neutral	+14.2 to −14.1
Slightly unfavourable	−14.2 to −42.7
Very unfavourable	−42.8 to −71.3
Extremely unfavourable	−71.4 to −100.0

TABLE 2
Demographics of policy influencers and the general public from Alberta and Quebec in the 2016 Chronic Disease Prevention Survey

Demographics	Alberta		Quebec	
	Policy influencer, % (*n*)	Public, % (*n*)	Policy influencer, % (*n*)	Public, % (*n*)
Sex				
Male	70.9 (107)	49.2 (591)	67.6 (73)	46.7 (560)
Female	29.1 (44)	50.8 (609)	32.4 (35)	53.3 (640)
Age				
18–45	9.6 (15)	32.9 (390)	25.7 (28)	34.8 (415)
46+	90.4 (141)	67.1 (797)	75.3 (81)	65.2 (776)
Education				
Up to postsecondary	–	20.5 (244)	–	18.8 (224)
Postsecondary	–	79.5 (944)	–	81.2 (966)
Household Income				
< $70 000	–	36.6 (383)	–	52.8 (564)
≥ $70 000	–	63.4 (663)	–	47.2 (504)
Education				
Up to trade/high school	–	57.7 (685)	–	48.2 (573)
At least some university	–	42.3 (503)	–	51.8 (617)
Sector				
Provincial government	19.2 (30)	–	10.2 (11)	–
Municipal authority	24.4 (38)	–	55.6 (60)	–
Workplace	23.1 (36)	–	24.1 (26)	–
School board	14.7 (23)	–	3.7 (4)	–
Media	6.4 (10)	–	2.8 (3)	–
Other	12.2 (19)	–	3.1 (4)	–

that Alberta policy influencers ranked as neutral. The most commonly coded type of tobacco control policy in our CDP Survey was "eliminate choice" (*n* = 12/29), while the least common policy type was "guide choices through incentives" (*n* = 1/29) (see Table 3).

The public survey items followed the same pattern of policy types as in the policy influencer survey (see Table 4). However, the subsurvey for the general public did not include policy options that were coded as "restrict choice," "enable choice" or "provide information." Among policy influencers taken as one group, the most supported policy option (NFP = 94.2, "extremely favourable") was "fully enforce current tobacco reduction legislation," a policy labelled as "guide choices through changing the default policy." The policy that had the lowest support (NFP = 29.1, "slightly favourable") among policy influencers was "sue tobacco companies to seek compensation for those who have been harmed by tobacco products and

nicotine addiction," categorized as a "reorient government action" policy.

Taken separately, policy influencers in Alberta and Quebec had different categorical levels of support for 15/29 tobacco control policy options. The two policy options that had the largest difference in support (i.e. a two-category difference) were:

- require cigarettes and other tobacco products be standardized in shape, size, colour and filters (Quebec was "extremely favourable" while Alberta was "slightly favourable"); and

- sue tobacco companies to seek compensation for those who have been harmed by tobacco products and nicotine addiction (Quebec was "very favourable" while Alberta was "neutral").

Among members of the public in both provinces taken together, respondents demonstrated the strongest support for strengthening procedures to prevent

illegal sales to minors, an "eliminate choice" category (NFP = 86.5, "extremely favourable"). In contrast, the policy options that garnered the lowest support from the public overall was increasing tobacco taxes by more than $1.00 per pack of 25 cigarettes, a "guide choice through disincentives" category (NFP = 41.9, "slightly favourable"). Similarly, public support for increasing tobacco taxes by up to $1.00 per pack of 25 cigarettes was the next least supported policy option (NFP = 43.6, "very favourable").

In contrast to policy influencers, respondents from the general public in Alberta and Quebec differed in terms of levels of support on only two policy options:

- ban cigarette smoking in all motor vehicles, an "eliminate choice" policy option (Alberta was "slightly favourable" while Quebec was "very favourable"); and

- increase tobacco taxes by more than $1.00 per pack of 25 cigarettes, a "guide

TABLE 3
Net favourable percentage of tobacco control policy options responded
by Alberta and Quebec policy influencers in the 2016 Chronic Disease Prevention Survey

Tobacco control policy options	Total		Alberta		Quebec	
	NFP, %	Missing, %	NFP, %	Missing, %	NFP, %	Missing, %
Eliminate choice						
Prohibit e-cigarette sales to minors (18 or 19 years of age, depending on the minimum tobacco age in the province)	92.6	9.9	91.1	9.2	94.7	10.9
Ban smoking in all public outdoor spaces where children are permitted (e.g. children's playgrounds, parks, sports fields and beaches)	91.4	7.6	86.6	5.7	98.3	10.2
Increase penalties for stores selling tobacco products to minors	84.9	7.6	86.7	4.6	82.3	11.7
Strengthen the procedures to prevent illegal sales to minors (e.g. mandatory ID check for anyone under 25, staff training, no employees under age 18)	81.4	7.6	80.6	5.2	82.5	10.9
Prohibit e-cigarette sales in locations where tobacco sales are banned	79.9	10.9	74.5	9.8	87.5	12.5
Actively enforce the existing ban on e-cigarettes with nicotine to prevent illegal/non-approved nicotine based e-cigarette products from being available in Canada[a]	76.8	14.2	71.1	12.6	85.0	16.4
Ban the use of water pipes (hookahs) in all public places where tobacco use is banned	75.8	20.5	73.9	12.1	79.3	4.7
Ban the use of e-cigarettes in all public places where tobacco use is banned[a]	69.9	11.9	63.4	12.1	78.8	11.7
Ban smoking at all workplaces, including outdoor worksites[a]	66.7	8.6	60.0	8.0	75.9	9.4
Ban cigarette smoking in all group living facilities (smoking is currently allowed in designated smoking rooms)[a]	59.0	7.9	48.1	6.9	74.1	9.4
Ban all flavoured tobacco products, including menthol cigarettes[a]	53.0	16.9	42.5	16.1	67.6	18.0
Ban cigarette smoking in all motor vehicles[a]	51.1	7.9	37.4	6.3	70.4	10.2
Restrict choice						
Strictly regulate e-cigarette advertising and promotion, including prohibiting celebrity and lifestyle marketing, unsubstantiated health claims, retail promotion, youth targeted marketing and the co-branding of e-cigarettes with traditional cigarette brands	79.1	14.6	73.7	12.6	86.8	17.2
Require all tobacco retailers to obtain a special licence to sell tobacco products[a]	44.9	12.3	52.3	10.9	34.5	14.1
Guide choices through disincentives						
Increase tobacco taxes by up to $1.00 per pack of 25 cigarettes	59.4	16.9	58.4	14.4	60.8	20.3
Increase tobacco taxes by more than $1.00 per pack of 25 cigarettes	52.2	18.2	46.2	16.7	60.8	20.3
Guide choices through incentives						
Subsidize 100% of approved stop-smoking treatment costs, including nicotine replacement therapy (NRT)[a]	44.4	8.3	35.0	6.3	57.9	10.9
Guide choices through changing the default policy						
Fully enforce current tobacco reduction legislation	94.2	8.3	91.4	6.9	98.3	10.2
Require that e-cigarettes be visually distinct from regular cigarettes	86.3	17.9	84.7	17.2	88.5	18.8

Continued on the following page

TABLE 3 (continued)
Net favourable percentage of tobacco control policy options responded
by Alberta and Quebec policy influencers in the 2016 Chronic Disease Prevention Survey

Tobacco control policy options	Total		Alberta		Quebec	
	NFP, %	Missing, %	NFP, %	Missing, %	NFP, %	Missing, %
Require that all tobacco products be sold in plain and standardized packs with no promotional elements, except the brand name, and health warnings and a list of harmful ingredients and emissions[a]	64.1	13.2	55.0	13.2	76.6	13.3
Require cigarettes and other tobacco products be standardized in shape, size, colour and filters[b]	53.2	17.9	35.2	16.7	78.6	19.5
Ban signs that advertise the price and availability of tobacco products at point-of-sale	50.6	12.9	44.7	12.6	58.6	13.3
Enable choice						
Provide counselling and support programs for people who want to quit smoking	93.7	6.0	90.4	4.0	98.3	8.6
Require employer-provided support options, such as counselling or nicotine replacement therapy for workplaces where smoking is banned[a]	33.3	9.6	16.5	9.2	56.5	10.2
Provide information						
Implement mass media campaigns to educate the general public about the implications of tobacco use[a]	75.5	7.9	64.4	6.3	91.3	10.2
Deploy tobacco industry denormalization campaigns that educate the general public about the industry's deceptive practices[a]	67.3	12.9	50.6	11.5	90.8	14.8
Reorient government action						
Government re-allocation of 100% of any new tobacco tax revenue directly to disease prevention or wellness programs	84.8	8.3	81.5	6.9	89.6	10.2
Sue tobacco companies to recover health care costs resulting from deceptive and negligent marketing practices like targeting youth, lying about health effects, fighting laws, etc.[a]	46.8	11.6	31.6	9.2	68.8	14.8
Sue tobacco companies to seek compensation for those who have been harmed by tobacco products and nicotine addiction (Quebec smokers class action suit)[b]	29.1	12.3	12.3	10.9	52.7	14.1

[a] Indicates a 1-category qualitative difference in level of support between policy influencers in Alberta and Quebec.

[b] Indicates a 2-category qualitative difference in level of support between policy influencers in Alberta and Quebec.

choice through disincentives" policy option (Alberta was "slightly favourable" while Quebec was "very favourable").

Overall, policy influencers and members of the general public differed in terms of levels of support on only two policy options:

- ban the use of water pipes (hookahs) in all public places where tobacco use is banned, an "eliminate choice" category (policy influencers were "extremely supportive" while the public was "very supportive"); and

- increase tobacco taxes by more than $1.00 per pack of 25 cigarettes, a "guide choice through disincentives" category (policy influencers were "very

supportive" while the public was "slightly supportive").

Discussion

One of the central challenges in public health action is negotiating the tension between promoting individual autonomy and freedom versus promoting optimal health at the population level.[22] The findings from our research show this tension by identifying varying degrees of support for evidence-based tobacco control policy options that affect individual autonomy. Our results indicate that both the public and policy influencers had "extremely" or "very favourable" levels of support for the majority of tobacco control healthy public policies included in the CDP Survey. This is promising, as it suggests overall high

levels of acceptability among government, non-government and/or citizen stakeholders for policy and environmental interventions to reduce smoking and tobacco consumption. Our findings reveal tobacco control options that may be considered "quick wins" in the policy change process that would enable Canada in reaching its tobacco reduction goals.[1]

Among these "quick wins," we found policy influencers and the public favourably supporting tobacco control policies that target children and youth and policies that focus on electronic cigarette (e-cigarette) regulation. For example, policy influencers and the public were "very favourable" about banning the use of e-cigarettes in all public places where tobacco use is banned and "extremely favourable" about prohibiting

TABLE 4

**Net favourable percentage of tobacco control policy options responded
by the Alberta and Quebec general public in the 2016 Chronic Disease Prevention Survey**

Tobacco control policy options	Total		Alberta		Quebec	
	NFP, %	Missing, %	NFP, %	Missing, %	NFP, %	Missing, %
Eliminate choice						
Strengthen the procedures to prevent illegal sales to minors (e.g. mandatory ID check for anyone under 25, staff training, no employees under age 18)	86.5	0.3	84.3	0.3	88.6	0.3
Prohibit e-cigarette sales to minors (18 or 19 years of age, depending on the minimum tobacco age in the province)	80.5	1.7	79.6	1.8	81.4	1.7
Ban smoking in all public outdoor spaces where children are permitted (e.g. children's playgrounds, parks, sports fields and beaches)	78.4	0.3	72.6	0.3	84.3	0.3
Ban the use of water pipes (hookahs) in all public places where tobacco use is banned	64.4	14.0	60.7	6.8	68.7	21.2
Ban the use of e-cigarettes in all public places where tobacco use is banned	64.4	2.3	63.5	2.7	65.2	1.8
Ban smoking at all workplaces, including outdoor worksites	59.4	0.5	51.2	0.7	67.5	0.4
Ban all flavoured tobacco products, including menthol cigarettes	50.7	1.9	44.8	1.8	56.7	1.9
Ban cigarette smoking in all motor vehicles[a]	46.5	1.2	36.3	1.2	56.7	1.2
Guide choices through disincentives						
Increase tobacco taxes by up to $1.00 per pack of 25 cigarettes	43.6	2.3	43.6	1.8	43.5	2.7
Increase tobacco taxes by more than $1.00 per pack of 25 cigarettes[a]	41.9	2.0	39.2	1.8	44.7	2.1
Guide choices through incentives						
Subsidize 100% of approved stop-smoking treatment costs, including nicotine replacement therapy (NRT)	61.7	1.3	55.6	1.3	67.8	1.2
Guide choices through changing the default policy						
Require that all tobacco products be sold in plain and standardized packs with no promotional elements except the brand name and health warnings and a list of harmful ingredients and emissions	57.9	2.6	53.4	2.0	62.5	3.2
Government action						
Sue tobacco companies to recover health care costs resulting from deceptive and negligent marketing practices like targeting youth, lying about health effects, fighting laws, etc.	55.7	1.6	47.8	1.6	63.6	1.7

[a] Indicates a 1-category qualitative difference in level of support between the general public in Alberta and Quebec.

the sale of e-cigarettes to minors. Healthy public policy advocates in Alberta may find these results particularly interesting, as the province had not, as of April 2019, enacted legislation specific to the regulation of e-cigarettes.[41,42] Given this high level of support among survey respondents in Alberta, our results indicate an opportunity for public health advocates to capitalize on these results and advocate for policy and environmental interventions to regulate e-cigarettes in the province.

As part of our analysis, we used the NCB intervention ladder to assess policy support by its level of intrusiveness on individual autonomy. According to the NCB, more intrusive policies tend to require stronger justifications (i.e. that the intervention will produce the desired outcome despite losses of individual liberty) in order to garner public acceptability.[22] In other words, the least intrusive policy and environmental interventions tend to be most acceptable.[23] Nevertheless, we found considerable support among both policy

influencers and the general public for more restrictive policies higher on the intervention ladder (i.e. "eliminate choice").

The high levels of support for policies that "restrict choice" or "eliminate choice" may reflect Canada's long history of success with more restrictive tobacco control policies.[43] It may also have some relation to whether the survey respondents were smokers or nonsmokers, which would be predictable, but not a variable that we measured. However, a recent Canadian

survey found strong support even among smokers for tobacco control policies that expand beyond current legislative approaches, as many Canadian smokers regret having started smoking, are interested in quitting and plan to quit.[15]

Further, level of education is also a predictor of tobacco policy support.[15] In our survey, the vast majority of participants had completed postsecondary education, which may also have influenced the higher levels of support for more restrictive tobacco control policies.

Our findings from the 2016 CDP Survey reinforce that the level of intrusiveness on individual autonomy of healthy public policies is only one factor impacting attitudes towards tobacco control. While we found strong support for policies on the highest rungs of the intervention ladder, the lowest levels of support were for policies that "guide choice through disincentives" (a middle-of-the-rung policy on the intervention ladder), particularly among respondents from the general public. In our survey, members of the public were the least supportive of policies that increase taxes on packs of cigarettes (NFP values ranged from 43.6 to 41.9, depending on the specific policy). These lower levels of support are surprising given that it is unlikely that a majority of survey respondents were smokers (i.e. the prevalence of smoking in Canada was 15% in 2017,[2] and general public participants were sampled through random digit dialling) and these respondents would not be directly affected by such a policy. These lower levels of support suggest that policy preference may not only be affected by self-interest,[44] but also by more deeply rooted societal beliefs found in neoliberal political climates (i.e. where there is a strong preference for less state intervention).

In addition, certain strategies within the "reorient government action" level were also the least supported among policy influencers, particularly in Alberta (i.e. sue tobacco companies to seek compensation for those who have been harmed by tobacco products and nicotine addiction). These low levels of support are a challenge for public health advocates working to reduce tobacco use. In particular, fiscal policies have been found to be some of the most effective and potent strategies for changing behaviour.[3] Our survey findings suggest that health advocates may need to focus advocacy efforts on the public health impacts of fiscally based policy intervention to reduce tobacco consumption. One approach that has increased support for fiscally based policies to reduce tobacco use has been linking additional tax revenue with direct support for health promotion initiatives. For example, people who smoke have been found to be more supportive of taxes on tobacco products when the taxes were being used to fund health-related initiatives, rather than going into the general budget pool and funding other, non-health-related priorities.[44]

Overall, our findings indicate that both policy influencers and the general public reported comparable levels of support for the vast majority of tobacco control policy options presented in the 2016 CDP Survey. The only two cases where support differed were banning the use of hookahs in all public places where tobacco use is banned and increasing tobacco taxes by more than $1.00 per pack of 25 cigarettes. In both these cases, policy influencers indicated stronger support than members of the public. If policy influencers are taking a risk and looking to enact policy where public support is weaker, existing support is not always required prior to behaviour change, since support has been shown to increase over time following the enactment of legislation.[14,23]

Members of the general public in Alberta and Quebec had comparable levels of support for the majority of policy options (11/13). This finding is surprising, as previous research has shown that smokers in Quebec in particular had stronger support for tobacco control policies than their counterparts in Alberta.[15] In contrast, policy influencers in Alberta and Quebec disagreed on more than half (15/29) of the policy options. For example, policy influencers in Quebec were "extremely supportive" of policy options categorized as "provide information" (e.g. deploy tobacco industry denormalization campaigns that educate the general public about the industry's deceptive practices) while their counterparts in Alberta were "very supportive" (NFPs ranged from 90.8 to 91.3 in Quebec compared to 50.6 to 64.4 in Alberta). Despite "provide information" being the lowest level on the NCB intervention ladder, and thus the least intrusive, policies situated at this level did not garner the most support among policy influencers in Alberta. This too is surprising as, historically, this provincial government has favoured policies involving less government intervention.[45] However, it could be that "provide information" campaigns targeting the tobacco industry are perceived as being on a level of government intervention that differed from information pamphlets on smoking cessation framed as an individual choice. In contrast to the policy climate in Alberta, the policy climate in Quebec has been more supportive of state intervention, for example, through spending and taxation.[46] While Alberta has been historically defined as a "neoliberal democratic one-party state governed by a Conservative political party,"[45,p.258] Quebec has a history of a union-led, social economy defined by more state involvement.[47] Hence, it is not surprising that in the 15/29 policies where policy influencers differed by province in levels of support, policy influencers in Quebec indicated more favourable support in 14/15 of those areas. The different historical political climates (i.e. approaches to state intervention) in each province may explain these differences in levels of support.

Strengths and limitations

The CDP Survey was limited by its cross-sectional and mixed purposive (policy influencers) and random (general public) sample, which precluded longitudinal or inferential interpretation of results. Rather, we calculated NFP values, a measure developed in marketing research (where more motivated respondents are generally the norm) to facilitate decision making on market actions.[37] Similarly, we used NFP values in a similar fashion to better understand policy influencer and general public perspectives in order to make decisions about advocacy actions. Another potential limitation was the low survey response rate, although this was in keeping with many other similar surveys with professionals.[48,49] It also mirrors an overall decline in survey participation more generally.[50] The lower response rate made it difficult to analyze policy support by policy influencer subgroup, for example. While research has demonstrated that decreasing survey participation rates do not necessarily bias the results,[51,52] we did use a variety of strategies to reduce nonresponse bias, such as repeated follow-up calls and emails (according to participant group) to ensure we obtain the largest sample size possible.

A strength of this research is our focused examination of policy influencer and general public support for potential tobacco control policies in two Canadian provinces. To our knowledge, few studies in a Canadian context have examined the acceptability of tobacco interventions of government and non-governmental stakeholders, as well as the general public.[7,19,20] Although our survey was implemented in 2016, our findings still provide the most current overview of policy influencers and general public opinions on the acceptability of tobacco control policies in Alberta and Quebec at the time of writing. While it is possible that participants' opinions may have changed since 2016, previous research indicates that support for tobacco control policies tends towards increased acceptability over time.[23,53,54] Therefore, it may be the case that levels of support in the 2016 CDP Survey will follow a similar trend. Future rounds of the CDP Survey may benefit from including additional demographic variables that may have influenced levels of support (e.g. smoking status), as well exploring patterns of support over time, including a 2019 update on tobacco control policy options.

Another strength of this study was our development of the intervention ladder codebook,[38] a notable first effort at advancing the interpretability of the NCB intervention ladder category levels for healthy public policy research. This work helped increase the transparency of our findings and led to the development of the new category to "reorient government action." We believe other researchers may find the codebook we developed useful in interpreting the NCB intervention ladder, particularly for understanding the ethical implications of healthy public policy options that do not fit into the original ladder. Our use of multiple coders in the analysis process further increased the rigour of the codebook process.

A final strength of our study is that policy options presented to respondents were vetted by an expert group of community organizations, practitioners and researchers in tobacco control as being timely and evidence-based, therefore increasing the relevance of and uptake of our findings for policy action.

Conclusion

As the Government of Canada renews its commitment to tobacco control policy, aiming to significantly reduce the population-level burden of tobacco use,[1] it is important to examine policy influencers' and the general public's levels of support for potential interventions to help strategize tobacco control initiatives and activities. Our research showed that respondents considered nearly all of the tobacco control policy options to be "extremely," "very" or "slightly" favourable, even for policies that highly restrict or eliminate the autonomy of individuals. Policies that were viewed as particularly favourable were those that strengthen the regulation of emerging tobacco products (e.g. e-cigarettes) to align with currently regulated tobacco products and policies that target children and youth. Our study provides further insights into some of the barriers that health advocates may experience in achieving tobacco control policy progress. For example, while taxing tobacco products has been one of the most effective policy interventions for decreasing tobacco use,[6] we found it to be one of the least supported policies. We also found many differences in favourability between policy influencers in Alberta and Quebec, with the latter demonstrating stronger support for most policies. In order for Canada to reach its new target to reduce smoking levels to less than 5%, advocates will have to identify strategies to overcome barriers to effective policy interventions, helping to decrease tobacco-related harm through knowledge-brokering strategies that communicate the population-health benefits. Despite the nuances in levels of support reported in our study, we found that both policy influencers and the general public overall indicated favourable support for the vast majority of tobacco control policy options. These favourable levels of support are positive and should be encouraging for health advocates to push for stronger legislative action on tobacco control policies and interventions to meet Canada's 2035 targets.

Acknowledgements

Conflicts of interest

All authors declare no conflicts of interest.

Authors' contributions and statement

CIJN and KDR led the design of the project and obtained project funding. CIJN led survey development, fielding and oversaw analysis. JAM and KK conducted the analysis. KK developed the manuscript with critical editorial support from JAM, CIJN and KDR.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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At-a-glance

The Child Maltreatment Surveillance Indicator Framework

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Abstract

The federal health portfolio has conducted surveillance on child maltreatment as a public health issue since the 1990s. The Public Health Agency of Canada (PHAC) is now releasing the Child Maltreatment Indicator Framework, to take its place alongside other PHAC frameworks, such as the Suicide Surveillance Indicator Framework. Based on a scoping review of existing reviews and meta-analyses, this Framework, along with the online interactive data tool, presents child maltreatment outcome indicators and risk and protective factors at the individual, family, community and societal levels, disaggregated by sex, age and other sociodemographic variables. This Framework will function as a valuable resource pertaining to an issue that affects at least one in three Canadian adults.

Keywords: child maltreatment, physical abuse, exposure to intimate partner violence, neglect, emotional maltreatment, sexual abuse

Introduction

Child maltreatment is a public health issue, causing both immediate and long-term physical and mental health effects.[1] Surveillance data are key to policy and program efforts to prevent and address child maltreatment. The Public Health Agency of Canada (PHAC) is responsible for national surveillance of child maltreatment, including physical abuse, exposure to intimate partner violence, neglect, emotional maltreatment and sexual abuse.[2] PHAC currently collects data about child maltreatment from administrative data from child welfare agencies, proxy informant surveys and self-report surveys.

The Child Maltreatment Surveillance Indicator Framework (CMSIF) gathers available data on child maltreatment outcomes as well as risk and protective factors at the individual, family, community and societal levels to support research and policy development. The CMSIF, which is being released in this issue of Health Promotion and Chronic Disease Prevention in Canada, serves as a complement to other indicator frameworks released by PHAC. These include the Suicide Surveillance Indicators (SSI), the Canadian Chronic Disease Indicators (CCDI), the Positive Mental Health Surveillance Indicator Framework (PMHSIF) and the Physical Activity, Sedentary Behaviour and Sleep (PASS) Indicator Framework.

Methods

The CMSIF was developed using a scoping review method.[3] Article searches prioritized systematic reviews, meta-analyses and literature reviews that examined risk and protective factors related to any type of child maltreatment. References from retrieved article reviews were reviewed for additional citations. Relevant articles published in English between 2004 and 2016 and reports from public health organizations (e.g. the World Health Organization) were consulted. An initial list of approximately 45 to 50 indicators was reduced through consultations with child maltreatment surveillance experts as well as with the Family Violence Initiative member departments to verify that the final list of

Highlights

- The Child Maltreatment Surveillance Indicator Framework complements other indicator frameworks released by the Public Health Agency of Canada and presents available data on child maltreatment outcomes and risk and protective factors at the individual, family, community and societal level.
- One-third (34.1%) of the Canadian population aged 15 years and older have experienced at least one type of childhood maltreatment.
- Physical abuse was experienced most often (27.4%), followed by exposure to intimate partner violence (10.6%) and sexual abuse (8.1%).
- Factors such as parental mental illness, substance use and past experience of family violence can put children at higher risk of child maltreatment.

indicators was relevant and actionable within a public health approach.

Results

Data from the 2014 General Social Survey (GSS) indicate that more than one-third (34.1%) of the population aged 15 years and older have experienced at least one of the following types of childhood maltreatment: physical or sexual abuse by an adult and/or exposure to violence by parents or guardians (Table 1). Of the three types of childhood maltreatment, physical abuse was experienced most often (27.4%), followed by exposure to intimate partner violence (10.6%) and sexual abuse (8.1%).

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Because of the familial context in which most child maltreatment occurs, risk and protective factors focused on parental and/or family characteristics rather than child characteristics. Factors such as parental mental illness, substance abuse and past experience of family violence can put children at higher risk of child maltreatment.

Conclusion

Childhood experiences are a key social determinant of health.[4] The CMSIF provides available evidence about contexts and risk and protective factors to help target strategies to prevent and address child maltreatment.

The CMSIF is an evergreen document; it will be reviewed periodically and updated as new data become available. An online interactive tool on the Government of Canada's Public Health InfoBase will provide breakdowns for the indicators by sex, age, province/territory, immigrant status.

The data gaps identified in the framework, particularly those at the community and societal level, are being addressed through active data development using surveys and administrative data.

Conflicts of interest

The authors have no conflicts of interest to declare.

Authors' contributions and statement

AC, SQ, GW, MS and WH were involved in the design and/or conceptualization of the work, as well as the acquisition, analysis or interpretation of the data. FB, WH and TL were involved in the interpretation of the data, as well as drafting and revising the paper.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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TABLE 1

CHILD MALTREATMENT SURVEILLANCE INDICATOR FRAMEWORK

QUICK STATS, CANADA, 2019 EDITION

INDICATOR GROUP	INDICATOR MEASURE(S)	LATEST ESTIMATE	DATA SOURCE (YEAR)
OUTCOMES			
Childhood maltreatment[a]	% of the population aged 15+ years who report experiencing, before age 15 years, any of these three types of childhood violence: physical or sexual abuse by an adult[b] and/or exposure to violence by parents or guardians	34.1%	GSS–Victimization (2014)
	% of the population aged 15+ years who report experiencing, before age 15 years, physical abuse by an adult[b]	27.4%	GSS–Victimization (2014)
	% of the population aged 15+ years who report experiencing, before age 15 years, sexual abuse by an adult[b]	8.1%	GSS–Victimization (2014)
	% of the population aged 15+ years who report experiencing, before age 15 years, exposure to violence by parents or guardians	10.6%	GSS–Victimization (2014)
Police-reported child maltreatment	Incidence of police-reported family violence against children aged 0–17 years	233 per 100 000 children	UCR (2016)
Out-of-home placement	% of children 14 years and under who are in foster care	0.5%	Census 2016
Injuries due to child maltreatment, ED	Proportion of ED presentations for injuries due to child maltreatment, of total eCHIRPP cases, population aged 0–17 years	146.5 per 100 000 ED cases	eCHIRPP (January 4, 2011 to June 6, 2018)
Homicides of children	Number of police-reported homicides of children aged 0–17 years by a family member, per year (% out of all homicides of children)	0.4 per 100 000 children (47.4%)	Homicide Survey (2007–2016)
INDIVIDUAL-LEVEL RISK & PROTECTIVE FACTORS (PARENT/CAREGIVER)[c]			
Past family violence	% of adults with children[b] at home who report experiencing, before age 16 years, any of these three types of childhood violence: physical abuse, sexual abuse and/or exposure to violence by parents/guardians in the home	48.1%	CCHS–Mental Health (2012)
	% of adults with children[b] at home who report contact with a child protection organization before age 16 years, about difficulties at home	4.1%	CCHS–Mental Health (2012)
Mental illness	% of adults with children[b] at home with symptoms consistent with a mood and/or anxiety disorder in the past 12 months	5.7%	CCHS–Mental Health (2012)
Stress	% of adults with children[b] at home who report that most days are *quite a bit* or *extremely* stressful	27.2%	CCHS–Annual (2017)
Substance use	% of adults with children[b] at home who report consuming 5+ alcoholic drinks (4+ for females) on one occasion 12+ times in the past 12 months	19.3%	CCHS–Annual (2017)
	% of adults with children[b] at home with symptoms of drug abuse/ dependence, in the past 12 months	0.7%	CCHS–Mental Health (2012)
Social support	% of adults with children[b] at home who perceive a high level of social support	94.6%	CCHS–Mental Health (2012)
Resilience	In development – *parental coping skills*		
FAMILY-LEVEL RISK & PROTECTIVE FACTORS			
Family relationships	% of parents/guardians of children aged 1–9 years who report characteristics associated with high family functioning	91.1%	SYC–PMK (2010–2011)
	% of Grade 6–10 students who *agree* or *strongly agree* getting the emotional help and support they need from their family	64.8%	HBSC (2013–2014)
	% of Grade 6–10 students who *agree* or *strongly agree* to having a lot of arguments with their parents	21.7%	HBSC (2013–2014)
Family stability	% of children aged 1–9 years who *sometimes* or *often* are exposed to adults or teenagers physically fighting, hitting or trying to hurt others in their home, as reported by the parent or guardian[d]	2.6%	SYC–Child (2010–2011)
	In development – *presence of a non-biological transient caregiver in the home (e.g. parent's partner)*		

INDICATOR GROUP	INDICATOR MEASURE(S)	LATEST ESTIMATE	DATA SOURCE (YEAR)
Parenting	% of children aged 1–9 years who *sometimes*, *often* or *always* experience physical punishment as a form of discipline, as reported by the parent or guardian[d]	0.5%	SYC–Child (2010–2011)
	In development – *caregiver's low awareness of children's needs and/or developmental stages*		
Caregiver burden	% of adults with children[b] at home who report that caring for family is the main contributor of their day-to-day stress	18.1 %	CCHS–Annual (2016)
	In development – *special needs of a child that may increase caregiver burden*		
Early childbearing	% of first-born live births to mothers under the age of 20 years	5.3%	CVSB (2015)
Household income	% of the population under the age of 18 years in economic families living below low-income cut-offs, after tax	7.4%	CINS (2016)
COMMUNITY-LEVEL RISK & PROTECTIVE FACTORS			
Services availability & accessibility	In development – *community-based services for parents and families*		
Social environment	% of parents/guardians of children aged 1–9 years who are involved in volunteer organizations (school or church groups, community or ethnic associations)	33.9%	SYC–PMK (2010–2011)
	In development – *residential instability and/or neighbourhood impoverishment*		
Physical environment	In development – *proximity to outlets that sell alcohol*		
SOCIETAL-LEVEL RISK & PROTECTIVE FACTORS			
Healthy public policy	In development – *formal support systems for families*		
Cultural & social norms	In development – *social/cultural beliefs regarding physical punishment as discipline for raising and educating children*		
Inequality	In development – *children's rights*		

Abbreviations: CCHS–Annual, Canadian Community Health Survey – Annual Component; CCHS–Mental Health, Canadian Community Health Survey – Mental Health; CINS, Canadian Income Survey; CVSB, Canadian Vital Statistics – Birth Database (excluding Quebec); eCHIRPP, electronic Canadian Hospitals Injury Reporting and Prevention Program; ED, emergency department; GSS, General Social Survey; HBSC, Health Behaviour in School-aged Children; SYC–Child, Survey of Young Canadians – Child questionnaire; SYC–PMK, Survey of Young Canadians – Person Most Knowledgeable questionnaire; UCR, Uniform Crime Reporting Survey.

Note: "In development" refers to measures where their data source is currently not available or where more research is needed to identify a promising measure and data source.

[a] The estimates in this indicator framework were calculated in a manner consistent with those from the Statistics Canada report *Family violence in Canada: a statistical profile, 2015*,[5] using a slightly different version of the database. All positive responses to all childhood maltreatment questions were counted as indicating maltreatment. In contrast, the original analysis rules for the *Childhood Experiences of Violence Questionnaire* (CEVQ)[6] include all positive responses, except for two of the physical abuse subtypes (the less severe ones) and exposure to intimate partner violence if it occurred less than three times.

[b] An adult is defined as a person 18+ years; a child is defined as a person under 18 years.

[c] Parental characteristics, not child characteristics, were considered as risk or protective factors for child maltreatment. This is based on a public health perspective that parental risk factors may represent potential outcomes of child maltreatment (such as prenatal substance abuse or violence).

[d] In the SYC–Child, the person answering these questions is confirmed at the beginning of the questionnaire to be the Person Most Knowledgeable (PMK) about the questions. "Parent/guardian" is used here for simplicity.

Other PHAC publications

Researchers from the Public Health Agency of Canada also contribute to work published in other journals or books. Look for the following, published in 2019:

Alatab S, Sepanlou SG, Ikuta KS, […] **Badawi A**, et al. The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet Gastroenterol Hepatol. 2019. pii: S2468-1253(19)30333-4. doi:10.1016/S2468-1253(19)30333-4.

Burstein R, Henry NJ, Collison ML, […] **Badawi A**, et al. Mapping 123 million neonatal, infant and child deaths between 2000 and 2017. Nature. 2019;574:353-8. doi:10.1038/s41586-019-1545-0.

Mirza A, **Forbes JD**, Zhu F, Bernstein CN, **Van Domselaar G**, **Graham M**, et al. The multiple sclerosis gut microbiota: a systematic review. Mult Scler Relat Disord. 2019. doi:10.1016/j.msard.2019.101427.

Muraca GM, **Liu S**, Sabr Y, et al. Episiotomy use among vaginal deliveries and the association with anal sphincter injury: a population-based retrospective cohort study. CMAJ. 2019;191(42):E1149-58. doi:10.1503/cmaj.190366.

Pourshams A, Sepanlou SG, Ikuta KS, […] **Badawi A**, et al. The global, regional, and national burden of pancreatic cancer and its attributable risk factors in 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet Gastroenterol Hepatol. 2019;4(12):934-47. doi:10.1016/S2468-1253(19)30347-4.

Safiri S, Sepanlou SG, Ikuta KS, […] **Badawi A**, et al. The global, regional, and national burden of colorectal cancer and its attributable risk factors in 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet Gastroenterol Hepatol. 2019;4(12):913-33. doi:10.1016/S2468-1253(19)30345-0.

Tonmyr L, Lacroix J, Herbert M. The public health issue of ACEs in Canada. In: Asmundson GJ, Afifi TO, editors. Adverse childhood experiences: using evidence to advance research, practice, policy, and prevention. London (UK): Elsevier; 2020:185-208.

Young I, **Greig J**, Wilhelm BJ, **Waddell LA**. Effectiveness of food handler training and education interventions: a systematic review and meta-analysis. J Food Prot. 2019;82(10):1714-28. doi:10.4315/0362-028X.JFP-19-108.