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Original qualitative research

Perceptions of cannabis among adults aged 60 years and older in Canada: a qualitative study

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Abstract

Introduction: Since cannabis legalization in Canada, consumption by older adults has risen more rapidly than in other age groups. There is a need to better understand patterns of consumption, motivations, access, perceptions of risks and benefits, and how legalization has changed older adults' behaviours, especially across gender, and frequency of use.

Methods: We conducted 10 online focus groups with 72 participants aged 60 years and older, segmented by cannabis use frequency. Focus groups were held across five regions in Canada. Data were collected using open-ended questions and analyzed thematically.

Results: Analysis revealed five themes: common practices; general knowledge; perceived harms; perceived benefits; and changes in stigma and social acceptability following legalization. The participants used various consumption methods, primarily oral consumption of edibles (gummies, capsules and baked goods) and inhalation (vaping and smoking). Legalization may have decreased stigma associated with cannabis use. Both frequent and infrequent consumers noted the therapeutic benefits of cannabis, particularly for pain management and mental health, but many expressed concerns about potential physical and cognitive adverse effects, possible interactions with medications and a lack of trustworthy sources of information or guidance from health care providers.

Conclusions: The findings demonstrate the complexities of cannabis consumption among older adults, who have specific challenges and risks, and the need for comprehensive public education and support from health care providers. Targeted research and policy development to address the specific needs of this underrepresented population are urgently needed.

Keywords: *cannabis, older adults, legalization, public health, Canada*

Highlights

- We investigated the experiences, behaviours and perceptions of cannabis consumption among adults aged 60 years and older in Canada.
- Older adults consume cannabis for many reasons, including for physical and mental health and recreationally.
- There are gender differences in cannabis consumption, with females preferring edibles and topicals, and males preferring smoking and vaping.
- Both frequent and infrequent consumers worried about the physical harms of cannabis consumption, in particular the potential cognitive decline and the effects of smoking on the lungs.
- Despite legalization, cannabis-related stigma persists for older adults, although perceptions of stigma differ between frequent and infrequent consumers.

Introduction

Cannabis for medical purposes became formally available to people living in Canada in 2001. Authorization by a health care provider allowed individuals with specific medical conditions to obtain cannabis legally through licensed producers, to register to grow cannabis themselves or to designate another individual to produce it on their behalf.[1] In October 2018, Canada implemented the *Cannabis Act*, which legalized nonmedical (or recreational) cannabis use nationwide for adults aged 18 years and older.[2] This made Canada the second country in the world, after Uruguay, to legalize the use of nonmedical cannabis.

Acceptance of cannabis has progressively increased across all age groups, continuing

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a trend that began before legalization and reflecting broader changes in how people perceive cannabis and its risks and benefits.[3-5] Studies have shown that legalization has influenced older adults' beliefs and perceptions about cannabis, contributed to its destigmatization, fostered more positive attitudes toward it and increased its acceptance.[4-8]

These shifts in perceptions and behaviours among older adults were also reflected in national surveys. For example, the 2019 National Cannabis Survey found that adults aged 65 years and older were the fastest-growing population of cannabis consumers, increasing from less than 1% in 2012 to 6.6% in 2019, with 27.0% reporting first-time use within the past 3 months.[9] Similarly, the International Cannabis Policy Study found that past 12-month cannabis use significantly increased among adults aged 55 to 65 years, from 19.3% in 2018 to 24.5% in 2019, the first year after legalization, and has remained stable since (24.3% in 2020 and 25.6% in 2021).[10] This study also found that a large proportion of older individuals who use cannabis do so for physical or mental health reasons rather than recreationally.[10]

A public opinion study found that older Canadians perceived cannabis use to be relatively common, with many reporting using it for medical purposes, especially to manage pain, stress and sleep, as well as for recreational purposes.[11] Aside from these findings, little is known about cannabis use by older individuals, highlighting the need for targeted studies to understand and address the unique needs of this underrepresented population.

Cannabis use can have significant risks, including for new older adult consumers. First, there may be a discrepancy between older adults' perceptions of cannabis potency, based on past experiences, and the more potent products currently on the market. Dried cannabis products in Canada can contain up to 30% delta-9-tetrahydrocannabinol (THC), while chemically concentrated extracts (e.g. shatter, budder, wax) can contain up to 90% THC.[12] A recent systematic review found that the use of high-potency cannabis products, defined by the authors as concentrates (THC ≥ 60%), resin or hash (THC about 30%–50%), and high-potency herbal cannabis (THC 20%–30%) was generally associated with poorer mental health, problematic cannabis use and polysubstance use, although most of the included studies were of low quality.[13]

The consumption of high-potency cannabis products can lead to increased blood pressure, heart rate and anxiety and to dizziness and falls among older adults.[14-17] The variety of consumption methods, including smoking, vaping and oral consumption, may make managing dosages and understanding onset times more difficult, potentially resulting in unintentional overconsumption.

Other concerns include multimorbidity, interactions with existing medications and altered metabolic processing. Older adults have greater risk of chronic conditions (e.g. chronic pain, insomnia, and mood and cognitive disorders),[8] some of which can be exacerbated by cannabis use.[18,19] Cannabis can also impact the efficacy of medications, for example, blood thinners, sedatives and antidepressants.[20] Finally, age-related changes in liver and kidney functions[21,22] can affect the metabolism of cannabis and other medications, increasing the risk of drug interactions and adverse effects.[23] A recent scoping review found that cannabis use among older adults was associated with greater frequency of mental health issues, problematic substance use and acute health care use, with the harms outweighing any potential benefits and no clear benefit-to-risk ratio.[8]

In this present study, we examined older Canadians' perceptions of cannabis use and describe the differences between frequent and infrequent consumers, gender-specific preferences and consumers' concerns. We examined the methods, reasons and motivations for using cannabis, how older adults access cannabis, their perceptions of its harms and benefits and how legalization affected their use patterns and behaviours.

Methods

Ethics approval

Ethics approval was obtained from the Advarra Institutional Review Board (Pro00064863) (Columbia, MD, US). Advarra is a commercial IRB with operations in the United States and in Canada. Advarra complies with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2) to ensure adherence to the highest ethical standards.

Each study participant provided written consent at the beginning of each focus group session.

Study design

We used a phenomenological qualitative research strategy to obtain in-depth descriptions of older adults' cannabis use.[24] This approach is effective for exploring complex topics as it respects and emphasizes individuals' lived experiences. We adhered to the Standards for Reporting Qualitative Research.[25]

Participants

Individuals aged 60 years and older residing in Canada were recruited through CRC Research, a Canadian firm specializing in qualitative research recruitment. CRC Research used their database, referrals and social media outreach and contacting potential participants via phone. They also posted advertisements targeting specific age groups and locations on Facebook and Instagram (Meta Platforms, Menlo Park, CA, US).

Potential participants were contacted by phone and underwent a screening process to ensure that they met the following eligibility criteria: aged 60 years or older; feeling comfortable speaking in a group setting; and having access to a stable Internet connection and a suitable device. Information was also gathered on participants' geographical location (province or territory); community setting (rural, urban); gender (male, female, nonbinary or other gender identity); and cannabis use patterns (ranging from never used to infrequent or frequent use, for both medical and nonmedical purposes).

CRC Research supervisory personnel validated participants by compiling master lists to meet target quotas.

Cannabis use patterns were determined by asking the participants, "Have you ever tried cannabis, either for medical or nonmedical purposes? Would you say… yes, just once, yes, more than once or no?" The participants were then asked, "During the past 12 months, how often did you use cannabis, either for medical or nonmedical purposes? Would you say… never, once or twice, monthly, weekly,

daily or almost daily?" We refer to the participants who reported consuming cannabis weekly, daily or almost daily in the past 12 months as frequent consumers; to those who reported consuming cannabis monthly or once or twice in this period as infrequent consumers; and to those who reported not consuming cannabis at all in this period or who had used in the past but no longer do as non-consumers.

Reasons for use were determined based on responses to the following question, "Which of the following best describes the main reason you use cannabis? Would you say… nonmedical (recreational use), medical use with a medical document, medical use without a medical document, or both?"

Procedure and data collection

Data collection occurred over 10 online 90-minute-long focus groups conducted from 22 to 28 September 2022. The focus groups were facilitated by Quorus Consulting Group (Ottawa, ON) under the supervision of a research team member [RG]. A total of 72 participants took part. Each received a CAD100 gift card as compensation for their time and effort. (Detailed participant characteristics are available from the authors on request).

Focus groups were conducted in five regions: Western Canada (British Columbia); Central and Northern Canada (Manitoba, Alberta and the Northwest Territories), Ontario; Quebec; and Atlantic Canada (New Brunswick, Prince Edward Island, Nova Scotia and Newfoundland and Labrador). Each region hosted two focus groups: one for frequent cannabis consumers and the other for infrequent consumers and non-consumers.

Focus group sessions with participants residing in the province of Quebec were held in French while those in the rest of Canada were held in English. Each focus group included six to eight participants from rural and urban settings and of different ages and genders. Sessions were held using Zoom Workplace (Zoom Communications, San Jose, CA, US), which was also used for observation, recording and transcription.

Data collection involved open-ended interview questions guided by a moderation guide (available from the authors on request).

Data analysis

To explore participants' perception of cannabis consumption, we used inductive and deductive thematic analysis methods, as outlined by Braun and Clarke.[26] The interviews focused on participants' knowledge, attitudes and perceptions about the benefits and harms of cannabis consumption. These were analyzed using MAXQDA (VERBI GmbH, Berlin, DE).

Three health care researchers [BP, SN, JR] with expertise in substance use and qualitative methods conducted the analysis. Thematic analysis involved systematically identifying themes within the narrative data. The researchers read all the transcripts, discussed initial impressions, extracted relevant phrases and assigned codes to these phrases. These codes were then organized into themes and the themes were reviewed and refined for coherence and distinction.

A final report detailing each theme was prepared, ensuring trustworthiness through peer debriefing. Two team members [BP and SN] conducted the initial analysis and a third [JR] validated the conclusions. An audit trail documented methodological and analytic decisions, with data display tables and visual representations retained.

Results

Focus group analysis generated 13 subthemes, which were collapsed into five overarching themes: common practices when using cannabis; general knowledge about cannabis; perceived risks and harms of cannabis use; reasons for consumption and the perceived benefits; and stigma and social acceptability post-legalization (Table 1). We examine each of these themes and include quotations from the transcriptions to illustrate the themes.

Common practices when using cannabis

Methods of consumption

The focus group participants identified two primary ways for consuming cannabis: oral consumption, which involves ingesting edibles such as gummies, capsules and baked goods (e.g. brownies), and inhalation, which includes vaping and smoking using vape pens, blunts and bongs.

Those who said they preferred smoking cannabis over other forms of consumption often gave "familiarity" and "habit" as reasons. Smoking was more popular among males than females. A few frequent consumers preferred vaping for the immediacy of the "high" (compared to edibles), while some infrequent consumers discontinued vaping because of concerns about unknown adverse health effects.

Some frequent consumers said that they had transitioned from inhalation to oral consumption as they aged to avoid the negative effects of smoking and vaping on their lungs. In contrast, infrequent consumers said that they avoided edibles because of their strength, which could lead to unanticipated "highs." Female frequent consumers favoured edibles and topicals over smoking to avoid the taste and smell of cannabis and the negative health effects. Males, overall, had no product preferences.

> I also stopped smoking … I changed the way that I use cannabis, and it is more appropriate for me too in terms of my lungs. [Frequent consumer]

Both infrequent and frequent consumers also mentioned using topical applications to manage chronic or arthritic pain. Lotions and oils containing cannabidiol (CBD) and THC were often described as providing relief from pain.

Access to cannabis

Older adults obtained cannabis from various sources, including from someone they knew or via medical cannabis authorizations, online stores, legal cannabis stores on First Nations reserves or other legal cannabis retail stores. Frequent consumers obtained cannabis primarily through online stores or dispensaries, while infrequent consumers often mentioned getting cannabis through someone they knew. The infrequent consumers who used cannabis oil for chronic pain typically purchased it from legal cannabis retail stores to ensure its safety.

Frequent consumers noted that legalization had made it harder to obtain cannabis through non-legal sources such as via friends or family because of the increased control and higher prices of legal products:

TABLE 1
Themes and subthemes identified from focus group analysis

Theme/subtheme	Details / What we heard
Common practices when using cannabis	
Method of consumption	
	Three types: oral, inhalation, topical
	Frequent consumers prefer inhalation (familiarity, immediacy of effects)
	Gender differences: males prefer smoking and vaping; females prefer edibles and topicals
Cannabis access	
	Older adults obtain cannabis products from someone they know, via medical cannabis authorizations, legal cannabis stores on First Nations reserves, online sources and retail stores
	Frequent consumers obtain cannabis products from online or retail stores; infrequent consumers obtain cannabis products from someone they know
	Impact of legalization on cannabis access: legalization appeared to decrease access through friends and appeared to improve perceived access to edibles and topicals (among females)
Reasons for cannabis consumption and perceived benefits	
Physical benefits	
	Managing chronic pain, arthritic pain, aiding sleep, managing withdrawal symptoms, "natural alternative" or "lesser evil" compared to pharmaceuticals
Mental health benefits	
	Managing anxiety and stress, helping relaxation and improving concentration
Recreational use	
	Socialization, overcoming boredom, desire for "high"
	Gender differences: males are more likely to report recreational use
Perceived risks and harms of cannabis use	
Fear of harms to physical health	
	Fear of unknown adverse effects, concerns about smoking on lung health, fear of cognitive decline and dependency
Fear of penalization	
	Fear of penalization when travelling with cannabis products
	Concerns about impaired driving, including understanding variability in individual responses to THC, tolerance, product potency, the duration of cannabis effects, and the accuracy of detection methods for impaired driving, contributing to legal uncertainties
Risk of mixing cannabis with other substances, including prescription drugs	
	Concerns about interactions with alcohol and prescription and nonprescription drugs; personal experiences highlighting risks
General knowledge about cannabis	
Source of information about cannabis	
	Active sources: Health care providers, family, friends, cannabis dispensers
	Passive sources: Internet, TV, social media, scientific sources, personal use
	Desire for unbiased information; low satisfaction with health care providers' information
	No gender differences observed
Cannabis dosing and product labels	
	Uncertainty about effective dosages
	Learning via trial and error
	Varied understanding of CBD and THC levels
	Dissatisfaction with labels, need for clearer, more informative labels and supplementary materials to guide informed decision-making related to cannabis consumption
	No gender differences observed
Interactions with health care providers	
	Perceived lack of knowledge and training among health care providers
	Need for more informed and supportive health care providers
	Mistrust of health care providers' guidance

Continued on the next page

TABLE 1 (continued)
Themes and subthemes identified from focus group analysis

Theme/subtheme	Details / What we heard
Stigma and social acceptability post-legalization	
Stigma related to cannabis use	
Persistent stigma despite legalization (frequent consumers)	
No gender differences observed	
Social acceptability	
Increased acceptability in social circles, more open discussions	

Abbreviations: CBD, cannabidiol; THC, delta-9-tetrahydrocannabinol.

> The black market was going full tilt when it was not legal, and the prices were a lot lower. Again, the minute the government sticks their hands in anything, it's shot. [Frequent consumer]

Some female participants, mostly frequent consumers, found that legalization made it easier to obtain edibles and topicals. Male frequent consumers did not mention significant changes in how they obtained cannabis post-legalization.

Reasons for cannabis use and perceived benefits of use

Physical benefits of using cannabis

Many frequent consumers cited pain management, specifically chronic generalized pain or arthritic pain, as their primary reason for using cannabis. This was also the main reason infrequent consumers gave for using cannabis, particularly CBD in edible or topical form. Many frequent consumers also found cannabis to be an effective sleep aid. Some other participants mentioned that cannabis helped them manage their withdrawal symptoms when tapering off opioids or alcohol. Some infrequent and frequent consumers considered cannabis preferable to pharmaceuticals based on their perception of it having natural properties. Specifically, they described it as a "natural alternative" and the "lesser evil" compared to medications that contain "chemicals."

Mental health benefits of using cannabis

Many frequent cannabis consumers reported using cannabis to alleviate mental distress, specifically the management of anxiety symptoms and stress levels. A frequent consumer described, "I deal with anxieties, and I can tone myself down with a minute amount of edible."

Cannabis helped some participants manage other dependencies. For instance, a frequent consumer stated, "I have an alcohol addiction, so the cannabis helps me to stay away from that."

Some frequent consumers described positive cognitive benefits, such as a greater ability to relax and improved concentration. Infrequent consumers did not mention the impact of cannabis on any anxiety symptoms, although some did acknowledge its beneficial effects on relaxation and sleep.

Recreational cannabis use

Some frequent consumers, mostly males, reported using cannabis for recreational purposes, including to facilitate socialization with other cannabis consumers. They also mentioned that cannabis has helped them overcome feelings of boredom, helping them "pass the time." Some others used it for pleasure or because they "wanted a high."

Perceived risks and harms of cannabis use

Fear of harms to health

Many frequent and infrequent consumers mentioned that a significant reason for avoiding using cannabis was their concern about its effects on their physical health. This fear was more pronounced among infrequent consumers; they were particularly deterred by the unknown adverse effects of cannabis products. Many frequent consumers were also concerned about the impact of smoking on their lungs; some mentioned that they had switched from smoking to vaping or oral consumption to mitigate these risks.

Participants in both groups also expressed concerns about potential cognitive decline due to cannabis consumption. They often linked this fear to their advancing age. One infrequent consumer explained:

> Years ago, I would find, like, if I smoked, and then I went to work the next day, I'd find it hard to be really focused at work on complex problems. And so I'd usually just limit [my use] to the weekends. Now, I don't know whether it's because I'm getting older … you begin losing words when you're talking, you get people's names wrong, and stuff. [Infrequent consumer]

The perceived risk of developing a dependency on or getting addicted to cannabis was another concern participants in both groups shared. For example, frequent consumers often mentioned that they no longer "feel a buzz" because of their increased tolerance, which has discouraged them from continuing to use.

Many infrequent consumers described experiences where cannabis had either harmful effects or was ineffective:

> I can't smoke or anything.... Marijuana, when I was young, would make me paranoid. Everything was negative for me. Young people around me, the only thing that they have gotten from it are problems. No car, [poor] mental health. Personally, I have a pretty negative opinion. [Infrequent consumer]

Fear of penalization

Concerns about driving while impaired were prominent among participants in both groups. Most agreed that impairment is unsafe and could lead to severe legal consequences:

> Impaired operation of a motor vehicle terrifies me. I don't care what you're impaired by, whether you're sniffing glue, drinking alcohol, or smoking marijuana or eating edibles, impaired driving is a no-no. [Infrequent consumer]

Many participants remained uncertain about the guidelines regarding cannabis consumption and safe driving. Determining the appropriate waiting period before driving was challenging because of the different consumption methods and individual metabolic rates:

> … It's hard to tell if someone is high. If someone is drinking and staggering around, you know that. Some people are secret smokers, and if you're smoking, you're impaired and you shouldn't be driving, but people are not good at policing themselves. So, that to me was one of the only negative things about them legalizing cannabis—worrying about the effects when someone was driving. [Frequent consumer]

Many participants in both groups attempted to conceptualize the effects of cannabis on driving by comparing it to alcohol, and often referenced alcohol-related impaired driving limits to frame their understanding of appropriate cannabis consumption before driving. Discussions often included considerations of individual tolerance:

> It depends on the person and the strength of the joint. Someone said how strong it's gotten now […] Some people are drunk with one glass of wine and others can drink four, five glasses and they are still standing. [Frequent consumer]

Both infrequent and frequent consumers expressed concerns about the risk of penalization, particularly when travelling with cannabis products containing CBD or THC. This fear was due to the recency of legalization and their uncertainties about what is legally permitted. Some female frequent consumers reported pausing cannabis use when they started a family, citing the responsibility of motherhood and the potential for penalization. As one female participant explained:

> I used it a little bit when I was a teenage hippie, but then I had kids and had to live a responsible life. So, I actually didn't get around to that, not so much because I thought it would interfere with my mothering, but more because it was a risk if you had kids because back when I was having kids, you could lose your kids if you were caught with pot. [Frequent consumer]

Mixing cannabis with other substances

Both infrequent and frequent consumers expressed concerns about mixing cannabis with other psychoactive substances, such as alcohol, citing a lack of personal knowledge or understanding of potential interactions:

> I would be concerned about the effects of alcohol and cannabis on your mental state or if you get impaired because of the additional effect of cannabis and alcohol. [Infrequent consumer]

Many frequent consumers noted that the choice to mix cannabis and alcohol is subjective and individual tolerance varies:

> I think it's really an individual thing like, you know, to mix or not to mix … Some people shouldn't mix, period, you know. But some people can do [it] all and it's fine. [Frequent consumer]

Some frequent consumers also reported shifting from using alcohol to cannabis as they aged:

> I don't drink at all now … like I don't have a glass of wine. I have a little bit of a gummy or something like that. [Frequent consumer]

Participants in both groups also acknowledged the potential harms of mixing prescription and nonprescription drugs with cannabis:

> I think mixing any kind of drugs, whether it's cannabis and other drugs or just other drugs, can be dangerous if you don't know what you're doing. [Infrequent consumer]

Infrequent consumers noted that they were afraid that cannabis could be a gateway drug.

General knowledge about cannabis

Source of information about cannabis

The participants received information about cannabis from both active and passive sources. Active sources included health care providers, family and friends, and cannabis retailers, while passive sources included multimedia (Internet, TV, social media), scientific articles and personal experience of cannabis use. Both frequent and infrequent consumers most often learned about cannabis during informal conversations with family and friends or from TV and social media. Frequent consumers also mentioned learning about cannabis from cannabis retailers and from personal experience. Very few participants, regardless of frequency of cannabis use, mentioned learning about cannabis from scientific articles. However, some frequent consumers expressed a desire for credible and unbiased information, explaining that it was difficult to find:

> I don't think it's easy to find unbiased information. They're either trying to sell it to you or they're trying to keep you off of it. There isn't any place that you can get a balanced view. [Frequent consumer]

For infrequent consumers, having access to unbiased information was not a concern.

Cannabis dosing and product labels

Frequent consumers in particular reported uncertainty about the cannabis dosages needed to achieve the desired effects. They often had to resort to trial and error to find the appropriate dosage levels for managing pain effectively. Only a few were confident in their understanding of dosages and the specific effects of different amounts of cannabis.

Frequent consumers varied the levels of CBD or THC depending on their method of use. Those using topicals, such as creams or oils, generally had a better understanding of the CBD levels in products; those using oral or inhalation methods were more familiar with both CBD and THC levels. However, many frequent consumers were unaware of the exact THC content in products and used vague descriptors such as "low," "medium" or "high." Among those who mentioned specific numbers in milligrams or percentages, their estimates varied significantly, likely reflecting differences in product types, recall bias and individual interpretation. Frequent consumers were also dissatisfied with the labels on cannabis products, and describing them as uninformative and difficult to understand. Some suggested that supplementary materials, such as information pamphlets, could help clarify the labels and dosages. They also mentioned the need for larger fonts

and more detailed dosage information, particularly for edibles:

> I don't understand the labels.... All I know is it's half CBD, half THC and that's all.... [If it] says 1000 milligrams ... what does that mean? Maybe there should be pamphlets or something explaining what the labels mean. Instead of just, you know, what's in the package and the strength of each one. [Frequent consumer]

> How to calculate the dosage. We could start with which ones. An example, gummies, like we spoke of earlier. Is it two? Is it according to your weight? It's according to what? [Frequent consumer]

In contrast, infrequent consumers engaged less in the discussions about cannabis product labels and dosages. They said that when they looked at labels, it was primarily to check the cannabis content (THC, CBD or both). They often looked for products containing only CBD and were not unduly concerned about interpreting labels for dosage information.

Interactions with health care providers

Few participants (mostly frequent consumers) were satisfied with the information they had received from health care providers. Participants said that they often wished health care providers knew more about cannabis, its health effects and appropriate dosages. The consensus in both groups was that health care providers lacked adequate training on cannabis consumption, which made the participants hesitant about seeking their advice:

> I could bring it up with the doctor, but all he's going to come back with [is] "Well, I've done this study, I've read this research, I believe in this and we've got documented cases." It's just going to be hearsay. So, unless you go to someone that has that knowledge [and] that has patients that live it every day, you don't get an honest answer or the answer won't be truthful. [Infrequent consumer]

Many participants thought that health care providers should be better informed about cannabis. Participants in both groups felt that they knew more than their health care providers:

> My doctors tend to be similar in age to me, or maybe at most 10 years younger, and they grew up … when it was illegal. So, my knowledge is probably better than theirs. [Infrequent consumer]

Some participants in both groups mentioned that health care providers were curious about their cannabis use but lacked the necessary knowledge to provide proper guidance:

> We didn't discuss [their] knowledgeability … [They] were just more or less curious as to what my experience has been, so I would say, yes, they probably could stand a little bit of education on that. [Frequent consumer]

Some frequent consumers described experiencing financial difficulties when trying to obtain prescriptions* for medical cannabis and, consequently, turned to online sources or stores on First Nations reserves, where product purity is uncertain. They often considered going to a walk-in clinic or making an appointment with a doctor, but the reluctance of health care providers to prescribe cannabis for medical use left many seeking alternative sources.

Other participants, in both groups, emphasized the importance of health care providers being open-minded and willing to authorize cannabis, as this would make these consumers less hesitant about discussing their cannabis use with their providers:

> I consider it kind of like a supplement or like Tylenol.... Would I tell my doctor I use Tylenol? Unless she asked me, I probably wouldn't mention it. [Frequent consumer]

Stigma and social acceptability post-legalization

Stigma related to cannabis use

Frequent cannabis consumers indicated that although legalization may have reduced cannabis-related stigma among younger individuals, this stigma persists for older adults, and they still feel that they are doing something illegal. One frequent consumer emphasized the need to educate older adults to reduce stigma:

> When I was at the senior centre, a lot of [the people there] were against it because we grew up that way, right? Like weed is no good.... Maybe the older population needs to be taught that it's like a medicine, it's medicinal, it's helpful … rather than it's taboo. [Frequent consumer]

> It is legal today, [but] I still feel weird … I am uncomfortable … [it seems] set in stone that it is illegal. [Frequent consumer]

Despite the lingering stigma, some frequent consumers felt that there had been a slight shift in attitudes toward cannabis use. They said that they hoped that societal views would continue to improve. In contrast, most infrequent consumers felt that stigma decreased considerably following legalization.

Social acceptability

Both frequent and infrequent consumers observed an increase in the acceptability of cannabis use as discussions about it have become more common in their social circles, particularly among friends and family. Some infrequent consumers compared their past experiences with the current openness in discussing cannabis use:

> More people are talking about it and suggesting it to their friends. I find that when I'm in conversation with people my age, they say, "Well, I've tried this." [Infrequent consumer]

Discussion

Our findings indicate that older adults' perceptions, knowledge and practices related to cannabis consumption vary based on frequency of use, gender and personal experiences.

Frequent cannabis consumers, who use cannabis weekly or more frequently, do so primarily to manage chronic health

* In Canada, cannabis for medical purposes is not prescribed in the same way as drugs with a drug identification number, including certain cannabinoid drugs (e.g. nabiximols). Instead, cannabis products are authorized for medical use by a physician and sourced by these patients from a Health Canada–approved medical cannabis producer. That said, we use "prescribed" and "prescription" to reflect the terminology used by the study participants.

conditions like arthritis, chronic pain and insomnia. They also consume cannabis for mental health issues such as stress and anxiety and for improved concentration and relaxation. These findings are consistent with previous research that reported that medical uses or health purposes were the most common reasons for older people using cannabis.[10,11,27] A subset of frequent consumers in our study also used cannabis socially and recreationally, for example, to alleviate boredom and enhance social interactions. This "dual purpose" use, which demonstrates the distinct motivations for cannabis use, has previously been observed.[11,28] Concerns arise when individuals who require medical assistance or health care supervision use cannabis recreationally, as this is not tailored to their medical needs. This underscores the complex situations health care providers need to consider when providing medical guidance to individuals who use cannabis for medical and nonmedical purposes.

Data from the 2024 Canadian Cannabis Survey show that the use of dried cannabis by Canadians aged 16 years and older has steadily decreased since legalization, while the use of edible cannabis, including beverages, has increased.[29] Between 2018 and 2024, the perceived risk of smoking or vaping cannabis increased, while the perceived risk of eating or drinking cannabis did not change.[29] Despite this reported shift away from smoking and vaping and toward edibles, many of the participants in our study reported that they continue to prefer inhalation methods because these were familiar and because the effects were immediate. Others, however, had made the shift in order to reduce lung-related health risks.

Frequent consumers often learned about optimal cannabis dosages through trial and error because of a lack of clear guidance, which led to inconsistent experiences and potential health risks. They expressed a strong desire for more evidence-based information on dosages and effects. This highlights the need for comprehensive education tailored to the unique needs of older adult frequent consumers to allow them to make informed decisions. Importantly, in line with previous research,[11] the frequent consumers participating in our study often acknowledged that, while legalization has reduced perceived stigma, especially among younger individuals, it persists among older people. This may be associated with the historical portrayal and legal status of cannabis, which many may have internalized. This stigma might also reflect a generational divide regarding the normalization of cannabis, with youth considering recreational cannabis use an acceptable part of growing up (e.g. experimentational use), while older adults have different life expectations and perceived roles.[30] Nevertheless, the frequent consumers in our study were optimistic that societal attitudes will continue to evolve favourably.

Gender differences were evident among frequent cannabis users. Similar to gender differences documented in national surveys and other studies,[10,31-34] males were more likely to favour smoking and vaping, while females generally preferred edibles and topicals to avoid the taste and smell of cannabis smoke and the health risks associated with smoking. According to the 2023 National Cannabis Survey, males aged 25 years and older were more likely to use dried cannabis (70.2% vs. 48.4%) than their female counterparts, who more frequently reported using edibles (62.7% vs. 51.9%).[31] Similarly, although data from the International Cannabis Policy Study show that the dried flower is the product most commonly used by both males and females aged 55 to 65 years, females reported greater use of edibles, oral oils and topicals and males more commonly used the dried flower, hash and solid concentrates.[10] Females were also generally more cautious than males about the health risks associated with smoking cannabis, and opted for other consumption methods.[32-34]

We found that infrequent consumers generally approached cannabis use with greater caution than frequent consumers. They were often discouraged by the lack of information about potential adverse effects and by a fear of dependence on a possible gateway drug. Many infrequent consumers had found cannabis to be either harmful or ineffective at managing their physical conditions. The primary reason for trying cannabis was pain management, and these consumers generally purchased the oil from a retail store to be sure it was safe. Infrequent consumers did not emphasize the mental health benefits of cannabis as much as frequent consumers did, although some acknowledged that cannabis helped them relax and sleep.

In contrast to frequent consumers, infrequent consumers generally perceived that the stigma associated with cannabis use had decreased following legalization. This group may consider the legal changes "liberating," as these allow them to explore cannabis use without the moral and legal repercussions that may have inhibited them in the past. This difference in perception could be attributed to varying degrees of exposure. Frequent consumers, with a longer history and perhaps a deeper understanding of the implications of cannabis use, may have still been dealing with deep-rooted stereotypes and personal reservations. Infrequent consumers, potentially newer to the cannabis experience and therefore less troubled by past prohibitions, might merely perceive the benefits of the recent changes in the law.

Despite differences in usage patterns and motivations, frequent and infrequent consumers shared some common perceptions. Some viewed cannabis as a natural alternative to pharmaceuticals, and therefore a "lesser evil" compared to conventional medications, a perspective also observed in other studies.[27,28] However, there is insufficient high-quality clinical evidence showing that cannabis is effective in the treatment of most health conditions and particularly as a first-line treatment.[35] A systematic review and meta-analysis of randomized clinical trials concluded that medical cannabis and cannabinoids—both prescription cannabinoids and plant-based preparations—provide few benefits in the management of chronic non-cancer and cancer-related pain, with the quality of evidence low.[36] Other research has shown that the effectiveness of cannabinoid products such as THC and CBD and pharmaceutical formulations with standardized THC to CBD ratios (e.g. nabiximols, dronabinol, nabilone) have limited and inconsistent effectiveness in treating mental health disorders such as depression and anxiety.[37-39]

Consequently, the College of Family Physicians of Canada recommends limiting the use of medical cannabinoids in general and restricting their use for neuropathic pain, palliative care, chemotherapy-induced nausea and spasticity due to multiple sclerosis or spinal cord injury.[40] For example, nabilone (Cesamet)[41] is approved for severe nausea and vomiting as a result of cancer chemotherapy, nabiximols (Sativex)[42] for spasticity in multiple

sclerosis and CBD (Epidiolex)[43] for certain treatment-resistant childhood seizure disorders. Research examining cannabinoid efficacy for conditions like pain, anxiety, mood disorders, psychosis, neurodegenerative disorders and substance use disorders is ongoing.[44]

Concerns remain about the risks of cannabis dosing, adverse effects and interactions with existing medications in older populations. Both infrequent and frequent consumers were worried about mixing cannabis with prescription and over-the-counter drugs, explaining that they were often unaware of potential interactions. Because older adults may be managing comorbidities with various medications, there is a need for greater awareness of and more education about possible interactions.[45] In addition, many older adults may assume the potency of cannabis products to be similar to that of the cannabis they used decades ago. The higher THC levels of currently available products pose specific risks, especially for people with existing health conditions or receiving multiple medications, potentially causing complications such as increased heart rate, elevated blood pressure, anxiety and disorientation.[14-17] Another and often overlooked concern is that many CBD products contain trace amounts of THC, and consuming high doses of CBD may lead to sufficient THC exposure to result in intoxication or impairment.

Both frequent and infrequent consumers described having social and societal fears, such as the fear of penalization, particularly regarding travelling with cannabis products and impaired driving laws. Consumers in both groups were confused about how impairment is assessed. While THC concentration limits for impaired driving exist in Canada, the participants felt that these limits do not account for individual differences in tolerance, product potency, method of consumption and duration of effects. These concerns demonstrate the need for improved tools to accurately assess impairment, as well as targeted public education to raise awareness about cannabis use and impaired driving.

Another concern was confusion over cannabis product labels, with many study participants describing labels as difficult to understand. This finding aligns with data from the International Cannabis Policy Study,[10] which reported that most consumers' comprehension of THC levels in cannabis products is low. This emphasizes the need for clearer, more informative labelling.[46-48] This is particularly important given the legal context and the variety of new products available on the market. The Expert Panel on the Legislative Review of the *Cannabis Act* recently recommended improvements such as simplifying THC and CBD displays, allowing transparent packaging for dried flowers and using QR codes for detailed product information.[49] Implementing a standard THC unit in product labelling and packaging, and as part of consumer education, has also been suggested.[50] Ensuring the accuracy of product labelling is also crucial for promoting informed and safe consumption. Inconsistencies in the labelling of legal cannabis oil products sold in Ontario indicate a need for greater quality control, as variations may affect the ability of consumers to make informed choices.[51]

Consistent with other research,[11,52-55] the older adults participating in our study often noted gaps in health care providers' knowledge about cannabis. Some participants felt that they knew more than their health care providers about cannabis, which affected their confidence in the guidance they received. The participants emphasized the value of having informed and supportive health care providers to help them safely navigate cannabis use. Enhanced education and training for health care providers, including nurse practitioners, was seen as important for addressing questions about the therapeutic benefits, appropriate dosages, potential interactions with other medications and possible adverse effects of cannabis.

While a significant number of older adults use cannabis for medical purposes, or are interested in doing so, the lack of evidence supporting the efficacy of cannabis as a treatment for many of the conditions it is commonly used to manage (with the exception of neuropathic pain[16,40,56]) makes it difficult to provide validated guidance, particularly as older consumers often use cannabis for both medical and nonmedical purposes. This highlights the need for more research into medical cannabis. At the same time, cannabis and cannabinoids should not be considered the only solution to the mental and physical health issues older adults frequently experience. Greater attention is needed to address the high prevalence of these health challenges, along with increased investment in a range of effective treatment options, irrespective of whether these include cannabis and cannabinoids.

Limitations and strengths

Our study had some limitations. First, as an exploratory investigation, it provides a focused snapshot of frequent and infrequent cannabis consumers among older adults, which limits the generalizability of the findings to the broader population of older adults in Canada who use cannabis. Participants were recruited from a consumer panel database built through ad campaigns, referral programs, targeted recruitment initiatives aimed at reaching hard-to-reach populations and other methods. Although this recruitment strategy enhances diversity, the participants may not represent the range of people in the older population in Canada and our findings may not capture the challenges, perspectives and behaviours of individuals from rural areas, with lower socioeconomic status or different cultural contexts. In addition, it is possible that individuals who choose to join such panels have unique characteristics, beliefs or behaviours that could influence findings.

Second, the use of focus group methodology may have introduced self-selection bias, as participation was voluntary, potentially narrowing the diversity of views and experiences represented.

Third, participants may also have moderated their views in a group setting, either choosing not to divulge certain information or aligning their opinions with others to avoid disagreement.

Finally, we examined gender within a binary framework (males and females) as none of the participants identified as nonbinary or as having another gender identity. Consequently, the findings may not fully capture the perspectives and experiences of older adults with diverse gender identities. Similarly, the majority of participants identified as White, limiting the generalizability of the findings to other ethnicities. Future research should aim to explore perceptions of cannabis use across a broader spectrum of gender identities and among individuals from different ethnic backgrounds.

Nevertheless, our study has several notable strengths. It is one of the first to specifically address cannabis use by older adults, a population that is underrepresented in this research field. Our research addresses critical gaps in the literature by exploring the unique experiences, motivations, behaviours and perceptions of cannabis consumption in this population post-legalization. By differentiating between frequent and infrequent cannabis consumers, our research adds to the current knowledge by identifying how older adults integrate cannabis into their health care and social lives. Our findings also highlight important gender differences in consumption preferences and perceptions of health risks, contributing to a more comprehensive understanding of cannabis use patterns.

Finally, the qualitative nature of this research allowed for in-depth exploration of individual experiences, offering rich data that can inform future research, health promotion initiatives and policy decisions aimed at this growing and important population.

Conclusion

Our study contributes significantly to what we know about cannabis use among older adults in Canada. We emphasize the diverse reasons for use, methods of consumption and varying perceptions of cannabis-related benefits and risks, as well as binary gender differences in these patterns. As the landscape of cannabis legalization continues to evolve, it is essential to prioritize the needs and experiences of older adults in cannabis research and policy. Providing targeted education, clear guidelines and supportive health care environments can help mitigate the risks of cannabis consumption in this population.

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Conflicts of interest

None to declare.

Authors' contributions and statement

JR: Conceptualization, methodology, supervision, visualization, writing—original draft, writing—review and editing.

BP: Formal analysis, writing—original draft.

SN: Formal analysis, writing—original draft.

EW: Writing—review and editing.

NC: Writing—review and editing.

RG: Conceptualization, methodology, visualization, writing—original draft, writing—review and editing.

All the authors provided feedback, contributed to the revisions and approved the final manuscript.

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Original quantitative research

Inequalities in the burden of disease due to dementia, including Alzheimer disease, in British Columbia, Canada, from 2001 to 2022

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This article has been peer reviewed.

Abstract

Introduction: Disability-adjusted life-years (DALYs) integrate mortality and prevalence (or incidence) data. DALYs can be used as a surveillance measure to assess dementia burden and inequalities.

Methods: We utilized dementia case and mortality counts from linked administrative data to estimate incidence, prevalence, cause-specific mortality and DALYs in people aged 65 years and older, from 2001 to 2022, in British Columbia, Canada. Dementia-specific mortality rates adjusted for changes in death certification practices over time were estimated using logistic regression that incorporated multiple cause-of-death data from vital statistics records. All measures were stratified by sex; DALYs were also stratified by age and area-based socioeconomic status (SES) quintiles. Average annual percent change (AAPC) in rates was estimated using joinpoint regression.

Results: Age-standardized dementia incidence and prevalence have declined since 2013, while mortality has increased by, on average, 1.6% per year since 2001 (95% CI: 1.4% to 1.8%). Age-standardized DALYs have increased by, on average, 1.4% per year (95% CI: 1.3% to 1.4%). DALY rates are highest in females aged 90 years and older but are increasing more rapidly in males. DALYs have declined for those in the least deprived SES quintile (AAPC: −0.6%; 95% CI: −1.0% to −0.3%) and conversely, have increased—with recent rates the highest—in the most deprived quintile (AAPC: 2.9%; 95% CI: 2.5% to 3.2%).

Conclusion: The socioeconomic gap in dementia disease burden has widened over time in British Columbia. DALYs are highest in females aged 90 years and older, but the overall gap between males and females has declined.

Keywords: *dementia, burden of disease, disability-adjusted life-years, material and social deprivation, socioeconomic status, mortality, population health, administrative health data*

Highlights

- Age-standardized disability-adjusted life-years (DALYs) have increased, on average, by 1.4% per year from 2001 to 2022.
- DALY rates by age group are highest in females aged 90 years and older, but they have been increasing over time at a faster rate for males in this age group.
- Dementia DALYs have declined for people living in the least socioeconomically deprived areas (average change of −0.6% per year) but increased in the most deprived areas (average change of 2.9% per year).
- Dementia-specific mortality rates from before 2015 may have been underestimated, contributing to an inflated upward trend from 2001 to 2022.
- After adjusting for underlying cause-of-death certification improvements, age-standardized mortality due to dementia has increased by, on average, 1.6% per year from 2001 to 2022.

Introduction

Dementia refers to a set of symptoms associated with progressive deterioration of cognitive functions caused by neurodegenerative and vascular diseases or injuries that affect daily living.[1] Alzheimer disease is the most common type of dementia,[2] making up approximately 60% to 70% of cases in Canada. Based on administrative health data, the Canadian Chronic Disease Surveillance System

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(CCDSS) identified 499 905 cases of dementia in people aged 65 years and older in Canada in the 2023 to 2024 fiscal year.[3] The Alzheimer Society of Canada estimates that the total number of cases will reach one million by 2030.[4]

Dementia risk increases with age and is higher for females;[3] associations between dementia incidence, prevalence and mortality and socioeconomic factors such as education, income, housing, employment, food security, stress and racial discrimination have also been reported.[5-13]

Continuous monitoring and evaluation of dementia inequalities in Canada is necessary to provide insight into the groups that are most affected and at risk, guide appropriate action and evaluate progress resulting from public health activities.[1] Population-level health administrative datasets contain information that can be used to track disease prevalence and mortality and associations with a few health determinants such as age, sex and geographical region.

The disability-adjusted life-years (DALYs) metric is a comprehensive surveillance measure, adopted by the 2019 Global Burden of Diseases, Injuries, and Risk Factors Study (GBD 2019),[14] that provides an integrated picture of the impact of disease prevalence and mortality on a population. DALYs are a direct sum of the number of healthy life-years lost due to illness (years lived with disability, or YLDs) and premature death (years of life lost, or YLLs). DALYs are comparable across diseases and allow for monitoring changes in population health and comparing the health of different populations. Data derived from the GBD 2019 demonstrate that globally, from 1990 to 2019, crude incidence and prevalence rates of dementia increased by 148% and 161%, respectively.[14,15] When rates were standardized by age, DALYs increased by, on average, 0.15% per year over the same period.[14,15]

The goal of this study was to estimate the dementia disease burden over time in the province of British Columbia, Canada, and to evaluate inequalities using population-level health administrative data combined with methods developed by the GBD 2019. Because of uncertainties in the accuracy of dementia mortality reporting over time, our investigation integrated a methodology to adjust local dementia mortality rates based on multiple cause-of-death (MCOD) data recorded on individual cause-of-death records.[16] Dementia health inequalities were evaluated in different age groups, in males and in females, and in those living in areas with different socioeconomic status (SES).

Methods

Ethics approval

This study was conducted as part of a population health research program approved by the University of British Columbia Research Ethics Board (Ethics REB #H22-01818) on 25 August 2022.

Dementia incidence, prevalence and mortality

Incidence and prevalence counts of dementia, including Alzheimer disease, in people aged 65 years and older were obtained from the British Columbia Chronic Disease Registry (BCCDR) produced by the Office of the Provincial Health Officer of British Columbia. The BCCDR tracks incidence and prevalence of 25 chronic conditions using predefined case definitions applied to administrative health databases, including practitioner visits (Medical Service Plan), hospitalizations (Discharge Abstract Database) and prescription dispensation records (PharmaNet). BCCDR case ascertainment methods are derived from algorithms developed and validated by CCDSS and incorporate British Columbia–specific criteria into the Canada-based algorithms.[3,17] The BCCDR identifies cases of dementia in people with one or more hospitalizations with a dementia code (International Classification of Diseases [ICD]-10 codes G30 and F00–F03 or ICD-9 codes 046.1, 290, 294.1, 294.2, 331.0, 331.1, 331.5 and 331.82); three or more medical visits with a dementia ICD code at least 30 days apart within 2 years; or one or more dementia drug dispensation records (donepezil, rivastigmine, galantamine or memantine). Incidence includes the number of new cases identified within a fiscal year, while prevalence is the total number of cases of dementia identified any time before the end of the fiscal year of interest in anyone aged 65 years and older and living in British Columbia at that time. Dementia deaths were counted from the British Columbia Vital Statistics Agency death registry where the underlying cause of death (UCOD) on the death certificate is attributed to dementia as defined by the GBD 2019 (ICD-10 codes: F00–F03, G30–G31.1, G31.8–G31.9; ICD-9 codes: 290–290.9, 294.1–294.9, 331–331.2) for selected individuals aged 65 years and older.

Adjusted dementia mortality rates

A recent report suggests that trends in increasing age-standardized dementia mortality rates (i.e. deaths with dementia as the UCOD) in countries such as Australia and the United States may not be accurate.[16] Changes in death certification and coding practices (i.e. describing the order, type and association of events that resulted in a person's death) and increasing awareness of dementia as a UCOD may have inflated the upward trend in mortality rates over the past two decades.[18-21] Adair et al. developed a regression model that incorporates MCOD data recorded on the death certificates of people with dementia to estimate the probability that dementia was the true UCOD.[16] We applied this methodology to estimate adjusted mortality rates in British Columbia and used these in calculating DALYs.

Briefly, all MCODs were extracted from vital events records from 1 January 2000 to 31 December 2022 for anyone aged 65 years and older who had dementia recorded on Part 1 or Part 2 of their death record. These MCODs were categorized into 17 cause-of-death variables (e.g. stroke, diabetes, cancer, injuries, etc.), as described by Adair et al.[16] MCODs that did not fall into these categories (about 13% of the entries) were not included. More than 60% of these unused codes were "garbage codes" (i.e. could not be official causes of death) as defined by the GBD 2019. Separate models were fit for males and females using logistic regression, where the dependent variable was dementia as the UCOD (yes or no) and the independent variables included the 17 MCODs, age (continuous), death year and death place type (home, hospital, non-hospital care facility or other). The resulting coefficients were then used to calculate the probability that dementia was the UCOD for each individual based on the available data. The coefficient for 2019 was used for the death year, because this year is hypothesized to have the most accurate death certification practices for dementia, assuming these practices are improving over time and that there were disruptions to determining cause of death during the

first 2 years of the COVID-19 pandemic. Individual probabilities of dementia as the UCOD were summed to obtain yearly adjusted dementia mortality counts.

Disability-adjusted life-years

DALYs were calculated as the sum of YLLs and YLDs for dementia in a given population, time and sex using the following equation:

$$DALY_{c,s,a,t,q} = YLL_{c,s,a,t,q} + YLD_{c,s,a,t,q}$$

where *c* stands for cause (dementia); *s* for sex (male, female, total); *a* for age (65 + years, by 5-year age group); *t* for time (by fiscal year, from 1 April 2001 to 31 March 2022); and *q* for area-based SES quintiles (detailed in the subsection, "Area-based SES").

YLLs were calculated using the following equation:

$$YLL_{c,s,a,t,q} = N_{c,s,a,t,q} \times L_a$$

where *N* stands for number of deaths and *L* for the gap between age of death and optimal life expectancy. Optimal life expectancy values were obtained from the GBD 2019 theoretical minimum risk life table.[22] This reference table was constructed based on the lowest observed age-specific mortality rates by location and sex from all locations with populations of more than five million in 2016.

YLDs were calculated using the following equation:

$$YLD_{c,s,a,t,q} = \Sigma\,[P_{c,s,a,t,q} \times DW_{c,s,a} \times SP]$$

where *P* stands for prevalence counts, *DW* for disability weight and *SP* for severity proportion. The severity proportion is the proportion of individuals in the population estimated to be experiencing mild, moderate or severe dementia.[23,p.966] GBD 2019 used a systematic review to collect information on the proportion of individuals in each dementia severity class, with information largely based on data from three population surveys in Australia and the United States. The Clinical Dementia Rating scale was used as the reference definition for severity classification, along with a doctor-given diagnosis, according to the *Diagnostic and Statistical Manual of Mental Disorders* (third, fourth or fifth edition) or ICD case definitions, as their reference definition for dementia. (For further details, refer to GBD 2019 Supplementary Appendix 1[23,p.964].)

The severity proportion is paired with the disability weight (mild, moderate or severe) to calculate overall YLDs. Disability weights were obtained from the GBD 2019[23,p.1547] and are further described by Salomon et al.[24] Disability weights are measured on a scale of 0 to 1 (where 0 equals a state of full health and 1 equals death) and represent the magnitude of health loss associated with a specific health status.

Area-based SES

Since socioeconomic factors are difficult to obtain from administrative datasets, DALYs were stratified according to the material and social deprivation index (MSDI) developed by the Institut national de santé publique du Québec.[25] The MSDI is used to monitor social inequalities in health. Deprivation scores (material deprivation based on income, education and employment; social deprivation based on marital status, lone parent status and living alone) are assigned to small area units (grouping between 400 and 700 persons) from the Canadian census called dissemination areas (DA). DAs are relatively homogeneous in terms of socioeconomic conditions and are linkable to postal codes found in administrative databases. However, some DAs are excluded from the MSDI because of low population numbers, collective households or other factors. Many individuals with dementia live in facilities where DA-level census data are suppressed; that is, 34% of prevalent dementia cases in the BCCDR from fiscal year 2016 to 2017 lived in a DA with no deprivation score.

To overcome this limitation, we first imputed missing deprivation scores by classifying the corresponding DAs as urban or rural (i.e. lying within or outside, respectively, a census metropolitan area or census agglomeration) using Statistics Canada's Geographic Attribute file.[26] For DAs with missing scores, the smallest geographical area (census tract < census subdivision < census division) with available deprivation scores and with the same urban/rural assignment was identified and the median value of the scores within that region were assigned to that DA.

With each census cycle (2001, 2006, 2011 and 2016), DA boundaries changed (substantial changes in 2001 relative to 2006, and minor changes in 2011 and 2016). New deprivation scores were calculated and assigned to those DAs. In our dataset, each person was linked to a 2016 DA, but because our dataset contained cases going back to 2001, we used MSDI scores calculated over time and imputed a score for each fiscal year. We did this by geographically aligning the 2016 DAs with DAs from previous cycles using the R package tongfen (R Foundation for Statistical Computing, Vienna, AT), which facilitates joining disparate spatial boundary data together into a common geographical region. First, tongfen was run with all four census cycles to join the 2001 to 2016 DA data. This resulted in a file that underwent substantial aggregation into new hybrid-DAs that are relatively large compared to regular DAs. Tongfen was run a second time using only 2006 to 2016 DA data, which underwent less aggregation, largely maintaining original DA sizes. The two datasets were joined, keeping only the 2001 to 2006 portion from the first step and the 2006 to 2016 portion from the second step, and each region was assigned an associated 2016 DA identification number.

Annual scores were derived from the 5-year MSDI scores using linear interpolation, that is, three separate linear functions were fit between each pair of proximate census years to allow estimating the scores for the intermediate years.

Finally, we combined deprivation index quintiles from the separate material and social deprivation quintiles (using the second suggested grouping method described by Azevedo Da Silva et al.[27,p.6]).

Data analysis and statistical methods

All analyses were performed in R version 4.2.2. Rates were calculated by dividing surveillance measure counts by mid-fiscal year population counts and reported per 100 000 population by fiscal year (1 April to 31 March, inclusive). Canadian 2011 Census population estimates were used as the standard population for age-standardization. Rates were stratified by sex (all measures) and by 5-year age group and SES quintiles (DALYs only).

We calculated uncertainty intervals (UIs) for YLLs, YLDs and DALYs using bootstrapping, sampling 5000 draws at each step of the calculations. Point estimates were calculated as the 50th percentile of

the sampling draws, the lower UI as the 2.5th percentile and the upper UI as the 97.5th percentile.

We calculated average annual percent change (AAPC) for discontinuous trends over time using joinpoint regression with the segmented package version 1.6-0 in R.[28] AAPC for continuous upwards or downwards trends where no significant breakpoints were detected were derived from the slope using a log–linear regression model with the following equation:

$$AAPC = 100 \times (\text{exponent}(\text{slope}) - 1).$$

Results

Age-standardized dementia incidence, prevalence and mortality over time, by sex

Dementia incidence in people aged 65 years and older declined, changing by an average of −0.4% (95% confidence interval [CI]: −0.7% to −0.2%) per year over the study period, with similar trends observed for males and females (Figure 1A; Table 1). Age-standardized prevalence rose by, on average, 5.5% (95% CI: 4.6% to 6.4%) per year from 2002 to 2004 and 2.0% (95% CI: 1.9% to 2.2%) per year from 2005 to 2013. The age-standardized prevalence has since declined, changing by −0.7% (95% CI: −0.9 to −0.6%) per year (Figure 1A; Table 1).

We estimated dementia mortality rates adjusted for changes in certification practices as higher than unadjusted rates across all years except 2022 (Figure 1B). Age-standardized dementia mortality has been trending upwards over the past two decades (Figure 1A); an AAPC of 3.3% (95% CI: 2.9% to 3.7%) was estimated using unadjusted rates while an AAPC of 1.6% (95% CI: 1.4% to 1.8%) was estimated using adjusted mortality rates. Of note, unadjusted mortality estimates show a decline in the rate of dementia mortality in the first year of the COVID-19 pandemic (March 2020 to March 2021) compared to the previous year, while adjusted mortality rates predicted an increase in dementia deaths in the first year of the pandemic.

Age-standardized YLDs, YLLs and DALYs due to dementia over time, by sex and age

YLD trends for dementia mirror prevalence and declined, changing by −0.8% (95% CI: −0.9 to −0.7) per year since 2013 (Figure 2). The AAPC for YLLs computed using adjusted mortality is 1.5% (95% CI: 1.3% to 1.6%). The AAPC for DALYs is 1.4% (95% CI: 1.3% to 1.4%). Similar trends were observed for males and females over most of the study period, but the AAPC is higher in males for all three measures. Also of note, YLLs and DALYs declined for females (−1.8% and −1.4%, respectively) and increased for males (4.8% and 3.3%, respectively) in 2022 compared to 2021, resulting in a narrowing gap for these measures.

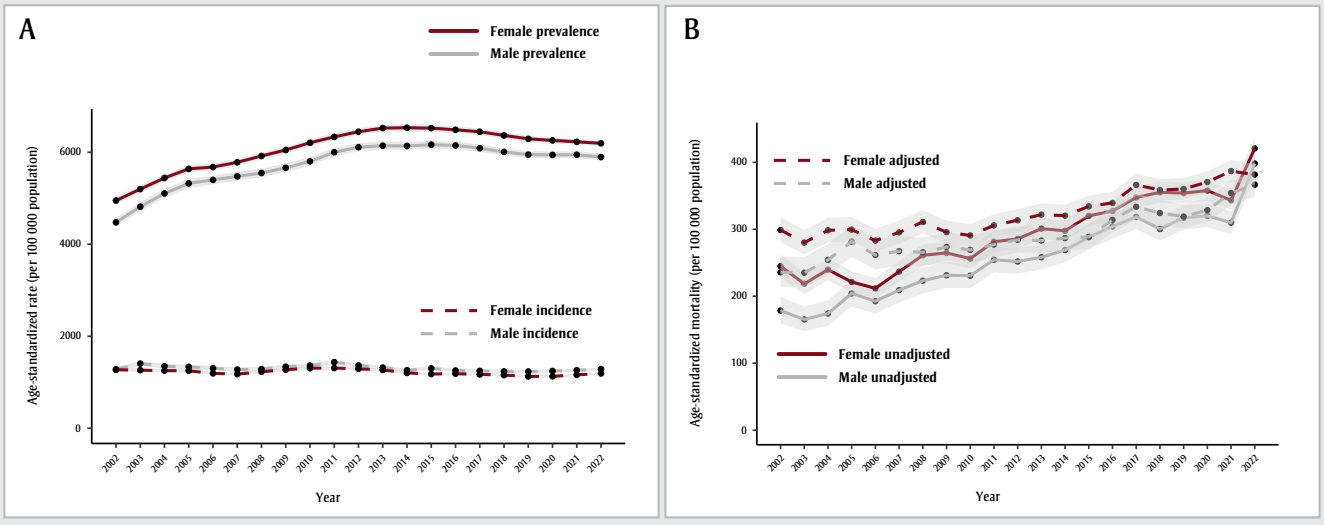
Age-specific DALYs due to dementia over time, by 5-year age group and sex

Figure 3 shows that the burden of disease due to dementia increases with age, as expected, and is higher in females than males in the highest age group, 90 years and older. Moreover, the greatest increase in burden over time is also occurring in the highest age group, with an AAPC of 1.8% (95% CI: 1.6% to 2.0%). Although DALY rates are higher in females aged 90 years and older than males in this age group, AAPC of DALY in males is significantly higher than in females (male AAPC: 2.9%, 95% CI: 2.4% to 3.5%; female AAPC: 1.9%, 95% CI: 1.7% to 2.1%).

Age-standardized DALYs due to dementia over time, by SES quintile and sex

DALYs stratified by SES quintile show a marked difference between those in the most deprived (quintile 5) versus the least deprived (quintile 1) regions (Table 2; Figure 4). Age-standardized DALYs dropped, changing by −0.6% (95% CI: −1.0% to −0.3%) per year in the least deprived quintile while they increased by 2.9% (95% CI: 2.5% to 3.2%) per year in the most deprived quintile. AAPCs in males

FIGURE 1
(A) Age-standardized dementia incidence and prevalence, by fiscal year and sex, individuals aged 65+ years, British Columbia, Canada
(B) Age-standardized dementia mortality, unadjusted and adjusted to take into account changes in death certification practices, by fiscal year and sex, individuals aged 65+ years, British Columbia, Canada



Notes: Years displayed on the x-axes denote the end of that fiscal year, e.g. 2002 stands for the 2001/2002 fiscal year.
The light grey shaded areas represent the 95% confidence intervals.

TABLE 1
APCs for individual segments and AAPC for the entire trend for age-standardized dementia incidence, prevalence, unadjusted and adjusted mortality, YLDs, YLLs and DALYs, total and by sex, individuals aged 65+ years, British Columbia, Canada

	Trend 1		Trend 2		Trend 3		AAPC, %
	Years[a]	APC, %[b]	Years	APC, %[b]	Years	APC, %[b]	
Incidence[c]							
Total	–	–	–	–	–	–	−0.4 (−0.7 to −0.2)
Male	–	–	–	–	–	–	−0.4 (−0.6 to −0.1)
Female	–	–	–	–	–	–	−0.5 (−0.7 to −0.2)
Prevalence							
Total	2002–2004	5.5 (4.6 to 6.4)	2005–2013	2.0 (1.9 to 2.2)	2014–2022	−0.7 (−0.9 to −0.6)	1.2 (1.1 to 1.3)
Male	2002–2004	6.8 (5.5 to 8.0)	2005–2013	2.0 (1.8 to 2.2)	2014–2022	−0.6 (−0.8 to −0.4)	1.4 (1.3 to 1.5)
Female	2002–2004	4.8 (4.1 to 5.6)	2005–2013	2.0 (1.9 to 2.1)	2014–2022	−0.7 (−0.9 to −0.6)	1.1 (1.1 to 1.2)
Mortality[c]							
Total	–	–	–	–	–	–	3.3 (2.9 to 3.7)
Male	–	–	–	–	–	–	3.7 (3.3 to 4.2)
Female	–	–	–	–	–	–	3.1 (2.7 to 3.5)
Adjusted mortality							
Total	2002–2010	0.7 (0.0 to 1.4)	2011–2022	2.3 (1.9 to 2.7)	–	–	1.6 (1.4 to 1.8)
Male	2002–2014	1.4 (0.7 to 2.1)	2015–2022	2.7 (1.9 to 3.6)	–	–	1.9 (1.6 to 2.2)
Female	2002–2010	0.3 (−0.5 to 1.2)	2011–2022	2.2 (1.9 to 2.6)	–	–	1.5 (1.2 to 1.7)
YLDs							
Total	2002–2004	5.4 (4.8 to 6.0)	2005–2013	2.0 (1.9 to 2.1)	2013–2022	−0.8 (−0.9 to −0.7)	1.2 (1.1 to 1.2)
Male	2002–2004	6.8 (5.5 to 8.1)	2005–2013	2.0 (1.8 to 2.2)	2013–2022	−0.6 (−0.8 to −0.4)	1.4 (1.3 to 1.5)
Female	2002–2004	4.8 (4.0 to 5.6)	2005–2013	2.0 (1.9 to 2.2)	2013–2022	−0.8 (−0.9 to −0.7)	1.1 (1.1 to 1.2)
YLLs							
Total	2002–2011	0.5 (0.1 to 0.9)	2012–2022	2.3 (2.0 to 2.6)	–	–	1.5 (1.3 to 1.6)
Male	2002–2013	1.1 (0.4 to 1.7)	2014–2022	2.8 (1.9 to 3.7)	–	–	1.8 (1.5 to 2.0)
Female	2002–2010	0.3 (−0.4 to 0.9)	2011–2022	2.1 (1.7 to 2.5)	–	–	1.4 (1.2 to 1.6)
DALYs[c]							
Total	–	–	–	–	–	–	1.4 (1.3 to 1.4)
Male	–	–	–	–	–	–	1.5 (1.3 to 1.7)
Female	–	–	–	–	–	–	1.3 (1.2 to 1.4)

Abbreviations: AAPC, average annual percent change; APC, annual percent change; DALYs, disability−adjusted life−years; YLDs, years lived with disability; YLLs, years of life lost.

[a] The year aligning with end of fiscal year period is denoted in the table (e.g. 2002 = 2001/2002 fiscal year).

[b] APC for each breakpoint is presented separately (if breakpoints were detected).

[c] No significant breakpoints were detected for incidence, mortality and DALY rate trends.

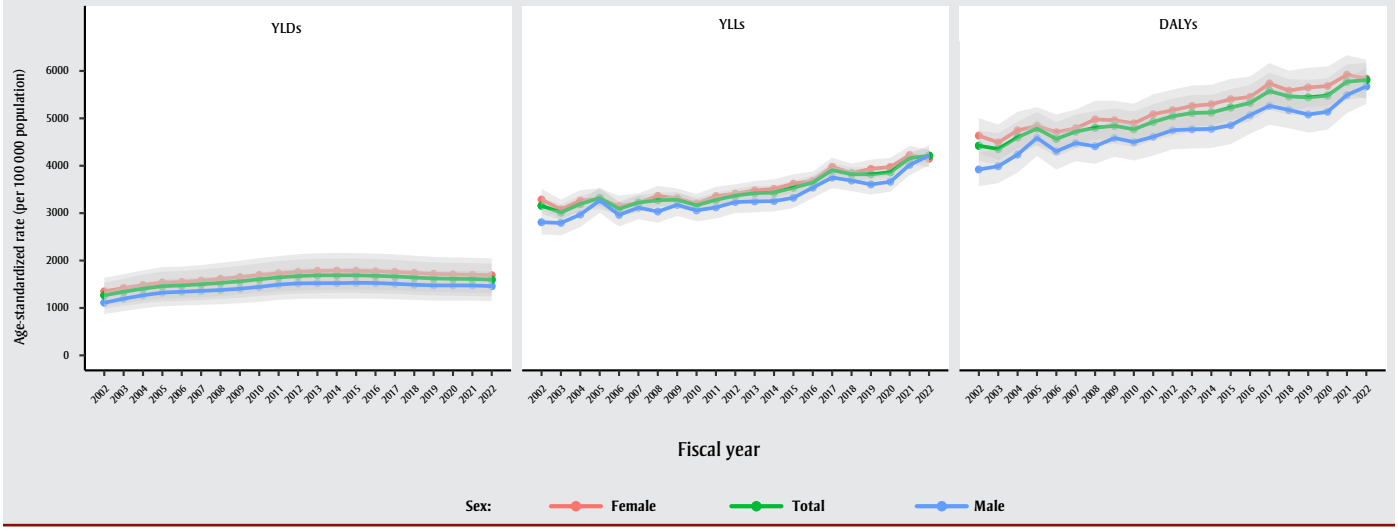
and females were similar in the most deprived quintile (male AAPC: 2.9%, 95% CI: 2.5% to 3.3%; female AAPC: 2.8%, 95% CI: 2.4% to 3.3%). However, in the least deprived quintile, we observed a decline among females (AAPC: −0.9%, 95% CI: −1.3 to −0.5%), while rates did not change significantly over time among males (AAPC: 0%, 95% CI: −0.5 to 0.4%).

Discussion

In this study we investigated the disease burden of dementia over 20 years in British Columbia and found declining incidence and prevalence and increasing mortality. The overall age-adjusted burden (DALY) is also increasing over time, with AAPCs highest in males, those aged 90 years and older and those living in regions with low SES.

Our modelling of adjusted dementia mortality rates supports the hypothesis that dementia as a UCOD may have been underreported in British Columbia, especially before 2015, which resulted in underestimated cause-specific mortality rates. This is reflected in the higher mortality rates modelled in earlier years, when MCOD data are used to adjust dementia mortality counts, compared to the number of deaths reported on vital statistics records. Still, even after accounting for improvements in UCOD certification practices, we measured an AAPC of 1.6% in age-adjusted dementia mortality, which is comparable to the change reported by Adair et al. for Australia and the United States.[16] This increase may reflect (1) changing MCOD reporting practices over time that were not taken into account by our model, and (2) a shift to dementia being a cause of death because

FIGURE 2
Age-standardized YLDs, YLLs and DALYs due to dementia, by fiscal year and by sex, individuals aged 65+ years, British Columbia, Canada



Abbreviations: YLDs, years lived with disability; YLLs, years of life lost; DALYs, disability-adjusted life-years.

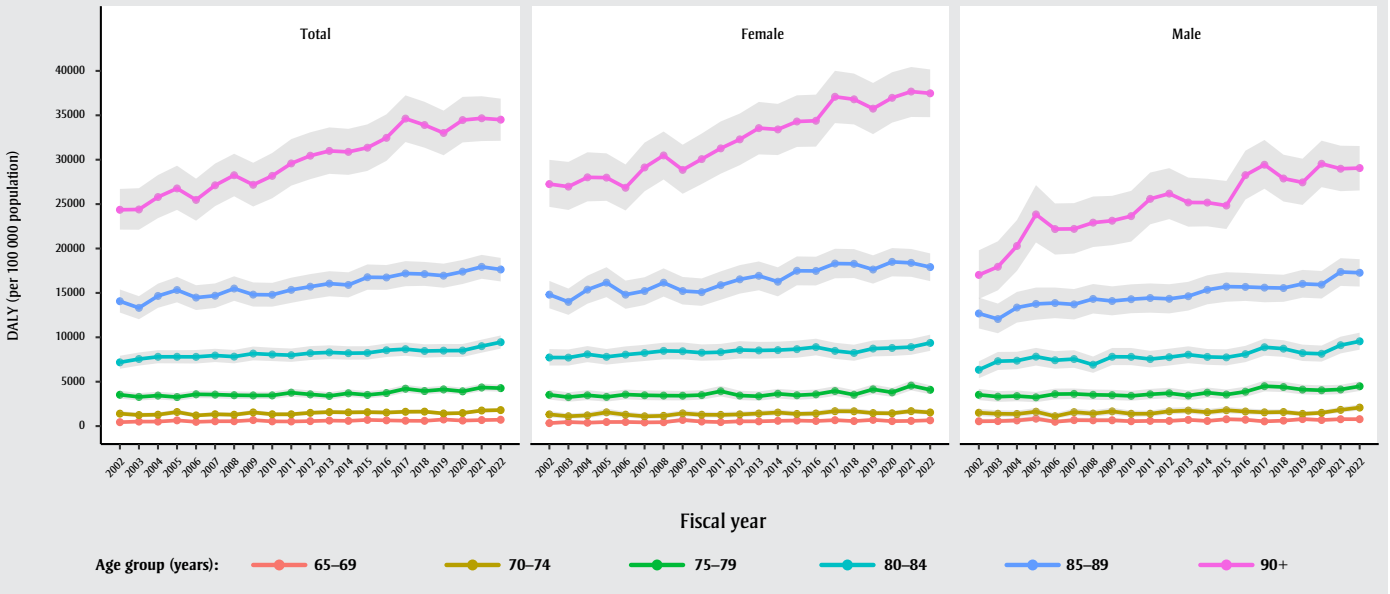
Notes: Years displayed on the x-axes denote the end of that fiscal year, e.g. 2002 stands for the 2001/2002 fiscal year.
The light grey shaded areas represent the uncertainty intervals calculated using bootstrapping (2.5th and 97.5th percentiles from 5000 draws).

other, previously more common causes (e.g. cardiovascular disease–related deaths) have declined.[16,29] These findings reiterate the need for caution when comparing dementia mortality rates derived from vital statistics over several years and that, whenever possible, modelling approaches should be used to account for changes over time.

DALY data from our study show that, on average, the disease burden of dementia in British Columbia has increased by 1.4% per year. The GBD 2019 estimated that the dementia DALY rate per 100 000 population in Canada was similar in 2001 (309.07; 95% UI: 144.94–656.73) and 2019 (310.66; 95% UI: 145.73–648.29).[30] The difference in our DALY measurements are likely due to mortality estimates; the GBD 2019 estimated similar mortality rates in 2001 and 2019 in Canada,[30] which differs from our estimated 36% increase in dementia mortality from 2001 to 2022.

Stratification by age showed that DALYs are highest and increasing at the greatest rate among people aged 90 years and

FIGURE 3
Age-specific DALY rates due to dementia, by fiscal year, 5-year age group and sex, individuals aged 65+ years, British Columbia, Canada



Abbreviation: DALYs, disability-adjusted life-years.

Notes: Years displayed on the x-axes denote the end of that fiscal year, e.g. 2002 stands for the 2001/2002 fiscal year.
The light grey shaded areas represent the uncertainty intervals calculated using bootstrapping (2.5th and 97.5th percentiles from 5000 draws).

TABLE 2
AAPC in age-standardized DALYs due to dementia, stratified by SES quintile and sex, individuals aged 65+ years, British Columbia, Canada, fiscal years 2001/2002 to 2021/2022

SES quintile	AAPC[a], % (95% CI)		
	Total	Male	Female
1 (least deprived)	−0.6 (−1.0 to −0.3)	0 (−0.5 to 0.4)	−0.9 (−1.3 to −0.5)
2	1.4 (1.0 to 1.8)	1.7 (1.2 to 2.3)	1.3 (0.8 to 1.7)
3	0.6 (0.4 to 0.8)	0.6 (0.2 to 1.0)	0.7 (0.4 to 0.9)
4	2.9 (2.4 to 3.3)[b]	2.8 (2.2 to 3.3)[b]	2.5 (2.1 to 2.9)
5 (most deprived)	2.9 (2.5 to 3.2)	2.9 (2.5 to 3.3)	2.8 (2.4 to 3.3)

Abbreviations: AAPC, average annual percent change; CI, confidence interval; DALYs, disability-adjusted life-years; SES, socioeconomic status.

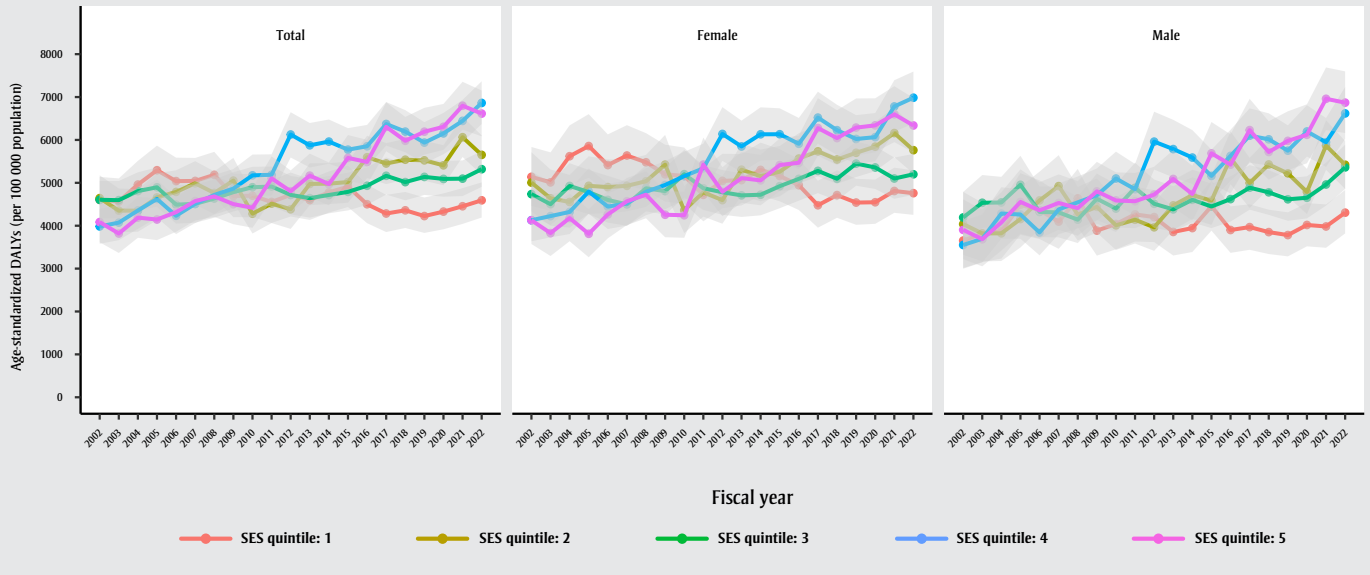
[a] AAPC was calculated from log–linear regression slope as the trends had no significant breakpoints, except where otherwise indicated.

[b] This AAPC was calculated from joinpoint regression due to two significant breakpoints in the trendline.

older. The higher AAPC in those aged 90 years and older is a combination of increasing prevalence before 2012 and rising mortality over most of the study period in this age group (data not shown). This may reflect a decline in deaths due to other causes and an increasing likelihood of dementia being the UCOD, but may also reflect a true increase in dementia burden in some populations. DALY rates in this age group have consistently been higher in females than in males over time, while in other age groups the DALY rates are similar in males and females. This suggests that the higher overall burden in females aged 90 years and older may be a consequence of their longer average lifespan. This burden may also be influenced by the underdiagnosis of dementia in younger people and those with milder stages of the disease, and that the disease is less likely to contribute to or be recognized as a cause of death in younger people.[18,19]

The differences in trends observed across SES quintiles are particularly important and highlight a widening socioeconomic gap in health outcomes.[11,31-33] SES comprises multiple factors that affect people's ability to engage in health activities, afford medical care and housing, and manage stress.[25,34-36] Lower SES is consistently associated with worse health outcomes, reflecting disparities in access to care, health literacy and other social determinants of health.[31,32,36,37] Many of the modifiable factors that influence risk of dementia are more prevalent in people with lower SES; these include diabetes, hypertension, smoking, alcohol consumption, depression, poor diet (i.e. resulting from food insecurity or barriers to and shifts away from traditional and cultural food consumption) and less formal education.[33-35,38,39] People in higher SES groups often have better access to cutting-edge diagnostic tools, novel medications and

FIGURE 4
Age-standardized DALYs due to dementia, by fiscal year, by sex and by SES quintile[a], individuals aged 65+ years, British Columbia, Canada



Abbreviations: DALYs, disability-adjusted life-years; SES, socioeconomic status.

Notes: Years displayed on x-axes denote the end of that fiscal year, e.g. 2002 stands for the 2001/2002 fiscal year.
The light grey shaded areas represent the uncertainty intervals calculated using bootstrapping (2.5th and 97.5th percentiles from 5000 draws).

[a] SES quintile 1 refers to the least deprived and SES quintile 5 the most deprived.

specialized care[40,41] that can lead to earlier detection, more effective management of dementia and improved survival rates. Reviewing the literature for this report highlighted the paucity of recent disaggregated data on dementia in Canada; such data are needed to inform policy and direct resources to the most at-risk populations.[38,42] Enhanced surveillance is thus needed to drive evidence-informed policies that build tailored health and social services and empower communities to improve health in meaningful and enduring ways.[34,42]

Strengths and limitations

Strengths of this study are that it utilized population-level health administrative datasets linkable to demographic information, including area-based SES, that allowed us to evaluate local disease burden and inequalities. Another strength was that we used a validated case definition to identify cases of dementia in British Columbia.[17]

A limitation of using this dataset is the impact of the COVID-19 pandemic on health care use, that likely influenced the reported rates for the fiscal years 2020 to 2021 and 2021 to 2022. Changes in trends observed during pandemic years should be interpreted with caution.[43] Dementia was reported on 36% of COVID-19 death certificates issued in Canada from January 2020 to February 2021, higher than any other comorbidity.[44] This is likely due to a combination of factors, including the overlapping and enhanced risk for serious COVID-19 illness associated with living with dementia, at older age and in a long-term care facility early in the pandemic.[45-49] Vital statistics records in our dataset predicted a decline in dementia deaths, while adjusted rates predicted an increase, in the first pandemic year (March 2020 to March 2021). There are two possible interpretations: (1) people who would have likely otherwise died from dementia, as predicted by MCOD modelling, died as a result of COVID-19 infection; or (2) difficulties in determining the true cause of death of people with dementia who contracted COVID-19 near their time of death may have resulted in inaccurate reporting of dementia mortality.[50,51]

Other limitations arising from the secondary use of administrative health data include potential misclassification biases, with mild cases of dementia likely underrepresented, and the incorrect assignment of some individuals as having dementia (i.e. due to medical coding errors or misdiagnoses). Although dementia mortality rates were adjusted for changes over time, death misclassifications likely persist in our dataset. In addition, the methodology used to compute DALYs relied on metrics developed by the GBD 2019, such as the optimal life expectancy table, disability weights and severity proportions; these may differ from equivalent metrics in Canada.

Conclusion

In this study we provided a methodological framework for surveillance of the disease burden of dementia in Canada. Our results underscore the importance of considering medical coding and death certification practices and socioeconomic factors in the interpretation of chronic disease statistics and highlight demographics that should be the focus of enhanced prevention and care in British Columbia.

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Conflicts of interest

The authors have no conflicts of interest to declare.

Authors' contributions and statement

ADO: Conceptualization, formal analysis, investigation, methodology, project administration, visualization, writing—original draft, writing—review and editing.

FE: Conceptualization, methodology, project administration, writing—review and editing.

SZ: Data curation, formal analysis, writing—review and editing.

BH: Conceptualization, supervision, writing—review and editing.

XY: Conceptualization, methodology, supervision, writing—review and editing.

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

This study was carried out without the involvement of the Government and is not meant to express their views or opinions.

Data availability statement

The individual level data used in this study were obtained from the British Columbia Ministry of Health Data Warehouse called Health*ideas*, which is not publicly accessible to protect individual privacy and confidentiality. Access to deidentified data may be obtained through one of the following platforms: Population Data BC (https://www.popdata.bc.ca/); the Data Innovation Program (https://www2.gov.bc.ca/gov/content/data/finding-and-sharing/data-innovation-program); or the Health Data Platform BC (https://healthdataplatformbc.ca/). The names of all the datasets used are in the methods section. Names of the variables used in this study may be requested by contacting the corresponding author.

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At-a-glance

Prevalence of childhood cancer in Canada: an analysis using 5-year, 18-year and 25-year limited-duration prevalence from the CYP-C data tool

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This article has been peer reviewed.

Abstract

Survivors of childhood cancers can face life-long health risks. In this study we describe the prevalence of childhood cancer in Canada by type, geographic region, year, age group and sex, using publicly available data in the Cancer in Young People in Canada (CYP-C) data tool. By 2021, 4325 people aged less than 20 years who had received a cancer diagnosis within the previous 5 years were still alive. The age-standardized 5-year prevalence increased by 12% over the past 15 years. Leukemia was the most prevalent childhood cancer. The CYP-C data tool provides comprehensive and timely public health surveillance statistics to understand the burden of childhood cancer.

Keywords: *neoplasms, prevalence, incidence, child, medical oncology, public health surveillance, survivors of childhood cancer*

Highlights

- By 2021, more than 1 in 1000 Canadians aged less than 20 years had received a cancer diagnosis before they were 15 years old.
- The age-standardized 5-year prevalence of Canadians surviving childhood cancer increased by 12% between 2006 and 2021.
- The online Cancer in Young People in Canada (CYP-C) data tool provides timely, accurate and accessible data about childhood cancer, including prevalence estimates, which are important for allocating resources and assessing impact.
- The CYP-C data tool allows for new comparisons by cancer type, geographic region, age, sex and year to help understand the burden of childhood cancer.

Introduction

Capturing cancer trends in children and youth is essential for understanding cancer burden.[1] Although rare, childhood cancers significantly impact mortality[2] and morbidity[3,4] among young people. Between 925 and 1000 children aged less than 15 years are diagnosed with cancer every year in Canada, and as of 2020, 86% had survived for 5 years.[2] Childhood cancer remains the second leading cause of death among children in Canada aged 1 to 14 years.[5]

Understanding the prevalence of childhood cancer is important for health system planning, resource allocation and assessing the impact of cancer.[6-8] Childhood cancer survivors require life-long survivorship care because of therapy-related complications, known as late effects.[3] Clinical guidelines for screening and management of late effects can improve long-term follow-up care and quality of life for childhood cancer survivors.[3]

The Cancer in Young People in Canada (CYP-C) program is a national, population-based surveillance system that serves to improve pediatric outcomes.[9] The CYP-C program operates through a collaboration between the Public Health Agency of Canada (PHAC), the Canadian Partnership Against Cancer (CPAC) and the C17 Council. Data are collected from 16 pediatric hematology, oncology and stem cell transplant programs in Canada.[9,10]

The CYP-C data tool, hosted on the Government of Canada's Health Infobase (https://health-infobase.canada.ca/), is an online interactive tool that displays data on childhood cancer collected through the CYP-C surveillance system.[2] The data tool is the only pan-Canadian surveillance tool dedicated to childhood cancer. It supports the Government of Canada's Open Data initiative by providing timely, accurate and accessible data. Open Data aims to provide Canadians access to data produced, collected and used across the federal government.[11]

In 2024, the CYP-C data tool was expanded to include prevalence estimates over time

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by age group, sex, cancer type and geographic region. Prevalence estimates of childhood cancer were previously limited to specific provinces[5,12-14] or points in time[6,15-17] and were often not disaggregated by risk factors.[6,13,15-17] Estimates from studies of childhood cancer survivors in the United States[4] and the adult population in Canada[15] suggest that the prevalence of individuals with a history of cancer, including those in remission, has increased over time, likely because of improved survival.

This study aims to present prevalence estimates of childhood cancer in Canada, stratified by cancer type, geographic region and year using data shown in the CYP-C data tool. The prevalence estimates are based on cases diagnosed between 2001 and 2020 for 5-year limited-duration prevalence (LDP) and between 1992 and 2017 for the 5-, 18- and 25-year LDPs.

Methods

Data sources

The aggregated incidence and prevalence data used in this study were downloaded in March 2024 as CSV text files from the publicly available CYP-C data tool, which gathers data from two sources.

The first source groups data from all children (aged less than 15 years) presenting at one of Canada's 16 pediatric hematology, oncology and stem cell transplant programs with a diagnosis listed in the *International Classification of Childhood Cancer, Third Edition*.[18,19] Each case registered in the CYP-C is followed for up to 5 years after diagnosis. The Pediatric Oncology Group of Ontario (POGO) also shares their population-based pediatric cancer registry with PHAC; Ontario data are obtained from the POGO registry to complete the CYP-C dataset. Detailed information about CYP-C and POGO data are published elsewhere.[2,10,20,21]

The second source is the Canadian Cancer Registry (CCR), a population-based registry that includes data reported to Statistics Canada by provincial and territorial cancer registries. The CCR collects information about primary cancer diagnoses received by residents of Canada.[22] The Canadian Vital Statistics - Death (CVSD) database includes demographic and death information reported to Statistics Canada by provincial and territorial vital statistics registries.[23] Statistics Canada creates and shares with PHAC a linked CCR and CVSD file (CCR–CVSD).

Population estimates for Canada and the provinces and territories are based on census data from Statistics Canada.[24]

Statistical analysis

The number of incident cases refers to the number of children with a new diagnosis of childhood cancer (i.e. received before age 15 years). LDP refers to the number of people diagnosed with a childhood cancer over a specific length of time (5, 18 or 25 years) who are alive on a given date. Person-based cancer prevalence counts the number of individuals, rather than the number of cancers diagnosed. Each statistic is based on a single cancer per person.

We estimated 5-year LDPs based on the number of cases in the CYP-C diagnosed between 1 January 2001 and 31 December 2020 who were alive on or after 1 January 2006. To calculate 18- and 25-year LDPs, we used linked CCR–CVSD data on children aged less than 15 years diagnosed between 1 January 1992 and 31 December 2017 and alive on 1 January 2018. Data from Quebec are not included in the CCR–CVSD. Detailed methods are described elsewhere.[2]

Using the counting method, we estimated prevalence from incidence and survival data.[25,26] For estimates using CYP-C data, prevalence calculations were completed in SEER*Stat software.[27] We used the Kaplan-Meier method with monthly intervals, based on age at diagnosis, sex and cancer site, to adjust the estimate of the proportion of cases lost to follow-up. For estimates using CCR–CVSD data, individuals without a record of death were presumed to be alive by the end of each time frame.

Age-standardized prevalence proportions are presented per million and standardized to the 2011 Canadian population.

Suppression

To ensure confidentiality, case counts of less than 5 are suppressed. In addition, case counts were randomly rounded either up or down to a multiple of 5. Age-standardized proportions use unrounded prevalent case counts.

Results

By 1 January 2021, 4325 people aged less than 20 years who had been diagnosed with childhood cancer in the previous 5 years were still alive.

The most frequently diagnosed childhood cancer type in 2020 was leukemia; there were 320 new cases versus 965 new cases of all cancers combined (Figure 1). Among the children aged less than 15 years living with and beyond cancer, the most common cancer diagnosis was leukemia (1265 5-year prevalent cases in 2020).

The age-standardized 5-year prevalence proportion in the CYP-C increased by 12% over the past 15 years, from 463 per million in 2006 to 524 per million in 2021. At 14.7% and 20.5%, respectively, this increase is most striking in the Prairies (comprising the provinces of Alberta, Saskatchewan and Manitoba) and in Ontario (Figure 2).

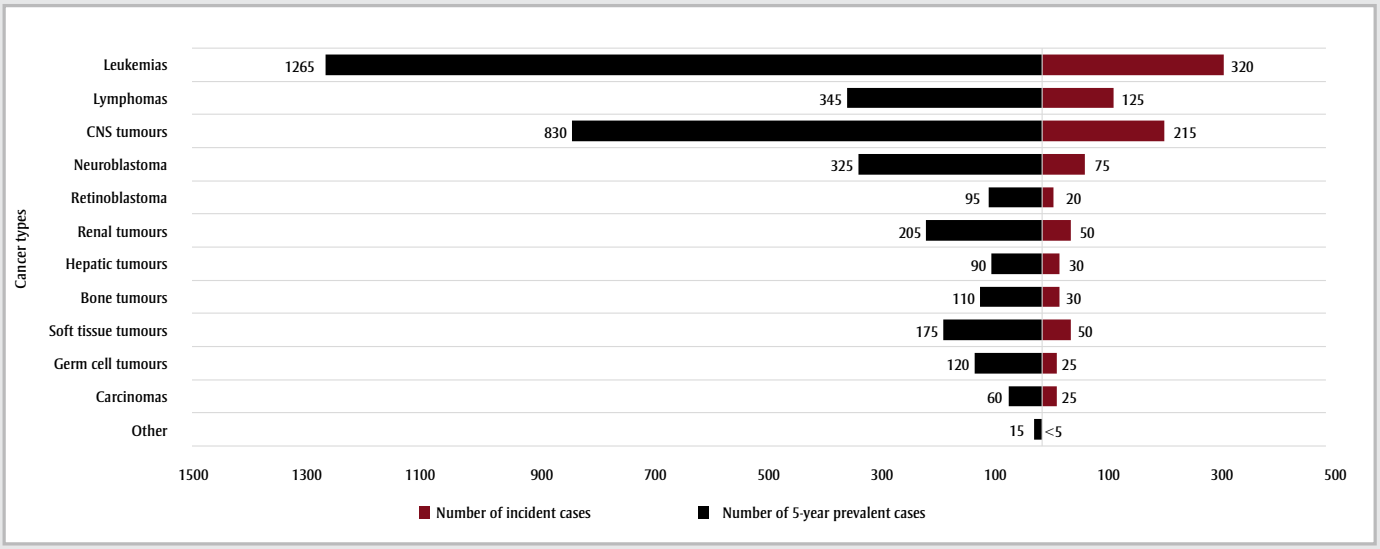
In 2018, 8615 individuals aged less than 20 years recorded in the CCR–CVSD had received a cancer diagnosis in their lifetime; the age-standardized 25-year LDP was 1365 per million. More than 60% of those diagnosed within the 25 years prior to 1 January 2018 were more than 15 years old. Because of their higher incidence,[2] males had a higher prevalence, though age distributions were similar in males and females (Figure 3).

Discussion

More than 1 in 1000 Canadians aged less than 20 years had received a cancer diagnosis before the age of 15 years. Prevalence combines the number of childhood cancer patients currently receiving treatment with cancer survivors who may need survivorship care and life-long monitoring.[15,28] Understanding the size of this population is vital for cancer control planning, health care resource allocation and research, and assessing impact.[1]

Our estimates are similar, although not directly comparable, to other estimates in Canada[14-16,29] and abroad.[7,8,30] For example, POGO[14] and Statistics Canada[29] found that by 2017 and 2018, respectively, 4700 and 4265 people living with and beyond cancer and aged less than 20 years had been diagnosed with childhood cancer in the previous 5 years. Age-standardized 5- and 20-year LDP proportions in Australia[7] and

FIGURE 1
Number of incident and 5-year prevalent cases,[a] children aged less than 15 years, by cancer type,[b] 2020, Canada



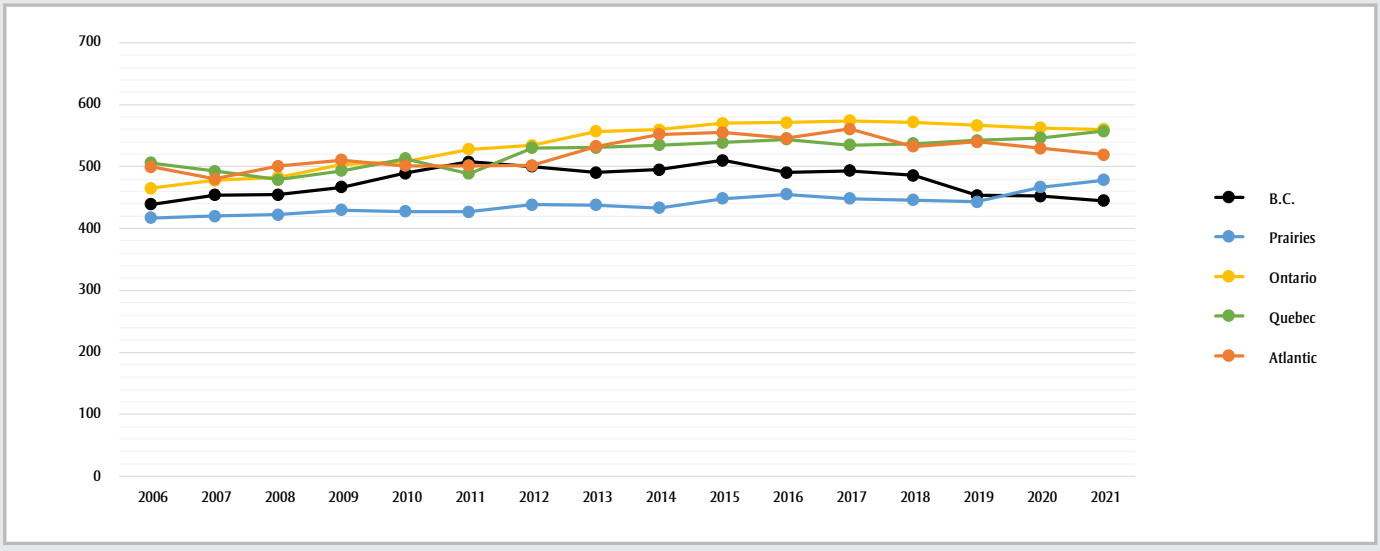
Data source: Cancer in Young People in Canada (CYP-C) data tool.[2]

Abbreviation: CNS, central nervous system.

[a] To ensure confidentiality, counts were randomly rounded to a multiple of 5 using an unbiased random-rounding scheme. Counts may not sum to the total because of this random rounding. Counts < 5 were suppressed.

[b] Classified according to the *International Classification of Childhood Cancer, 3rd ed*.[19] into 12 main groups. CNS tumours include benign and malignant tumours.

FIGURE 2
Age-standardized 5-year prevalence[a] per 1 000 000, children and youth aged less than 20 years, by province or geographic region[b] and year, 1 January 2006 to 1 January 2021, Canada



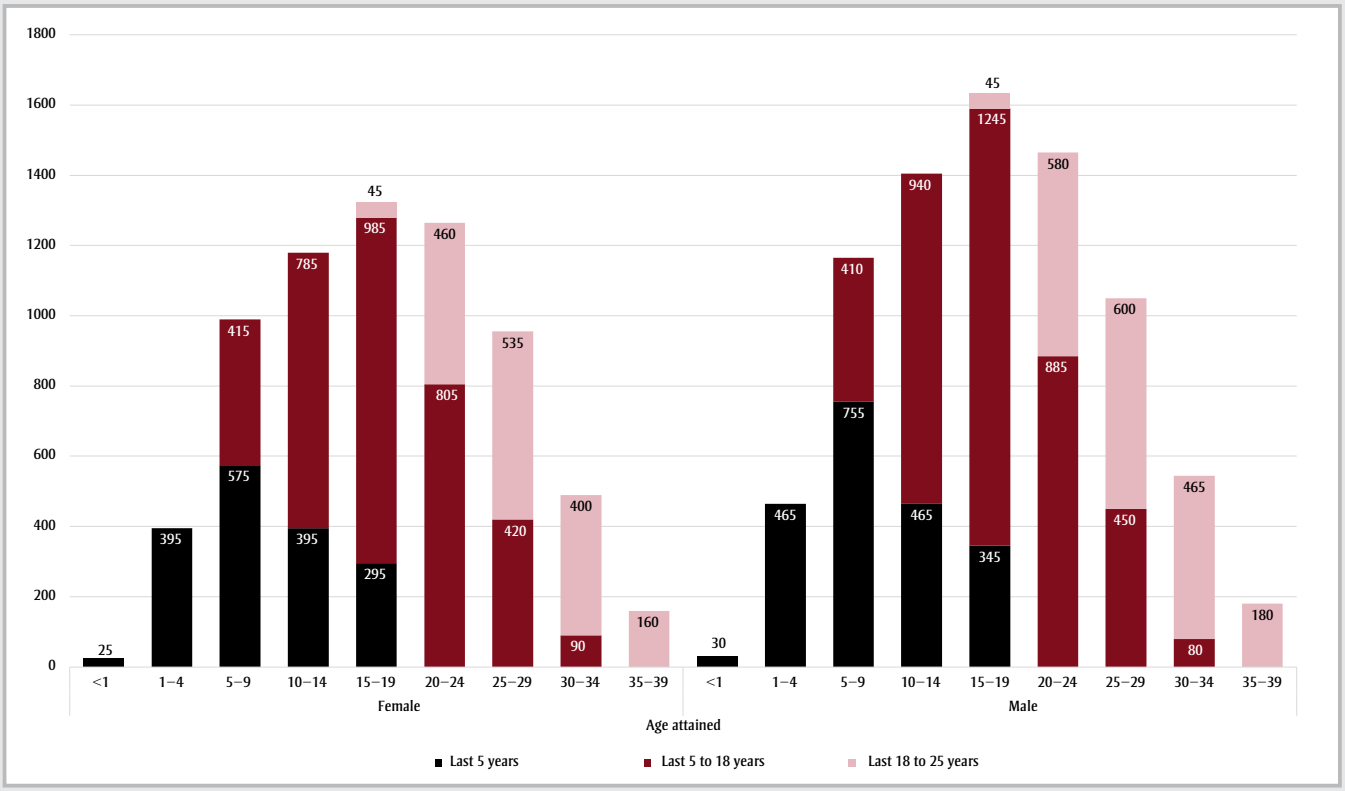
Data source: Cancer in Young People in Canada (CYP-C) data tool.[2]

Abbreviation: B.C., British Columbia.

[a] Age-standardized 5-year prevalence proportions are standardized to the 2011 Canadian population.

[b] The Atlantic region comprises the provinces of New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador. The Prairies comprise the provinces of Alberta, Saskatchewan and Manitoba. Data from Yukon, Northwest Territories and Nunavut are statistically unstable and are suppressed.

FIGURE 3
Number of 25-year prevalent cases,[a] by sex, attained age in years and time since diagnosis, 1 January 2018, Canada (excluding Quebec)



Data source: Canadian Cancer Registry – Canadian Vital Statistics Death database (CCR–CVSD).[22,23]

[a] To ensure confidentiality, counts were randomly rounded to a multiple of 5 using an unbiased random-rounding scheme. Counts may not sum to the total because of this random rounding. Counts < 5 were suppressed.

the Netherlands,[8] respectively, followed a similar trend to our 5- and 25-year LDPs.

The CYP-C data tool is valuable as other Canadian estimates are not reported by pediatric cancer type or by geographical region and age at diagnosis.[14-16,29] Proportions are similar across Canada, and the age-standardized prevalence has increased slightly over the last 15 years. Leukemia contributed to one-third of all incident and prevalent cases.

Having accessible, accurate and timely public health data is crucial for Canada.[31] The CYP-C data tool can be used to share childhood cancer information with patients and their families, health care professionals, policy makers, advocates and researchers.

Strengths and limitations

The CYP-C data tool includes Canadian childhood cancer data from the two most comprehensive and timely sources. These data allow for new comparisons by cancer type, geographic region, age group, sex and time, providing the ability to look beyond incidence to understand the burden of childhood cancer.

There are some limitations. The data tool only includes LDP data of Canadians aged less than 40 years with a history of childhood cancer as the CCR does not capture data before 1992. Childhood cancer survivors aged 40 years or older are also at risk for late effects of cancer treatment.[28] Future work will aim to include longer follow-up and complete prevalence across the lifespan to capture the full burden of childhood cancer.

When using data from the CCR, we assumed individuals to be living if there was no associated record of death. However, deaths that occur outside of Canada are not included, which could result in slightly overestimated prevalence. Also, all cases in Quebec were excluded because data sharing agreements prohibit data release.

The data tool employs suppression and unbiased random rounding to maintain privacy in public datasets.[32] These techniques have a greater impact on small populations (e.g. small provinces or territories), which could mask important geographic variations and changes in rates over time.[33]

Conclusion

In partnership with the CPAC and the C[17] Council, PHAC recently included prevalence data of individuals living with or beyond childhood cancer in the CYP-C data tool. This study characterizes the population of childhood cancer patients and survivors. The aim is to add more data, such as socioeconomic status, in order to improve public health surveillance in this population in the future.

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Commentary

Uncertainty communication, trust and health promotion

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Abstract

Health promotion is more effective when health communicators are considered trustworthy. However, health communicators must often deal with uncertainties in the knowledge base on which they rely. In this commentary, we discuss the benefits of acknowledging uncertainty, with caveats and best practices to cultivate trust. We recommend determining the type of uncertainty involved and selecting appropriate communication approaches. We also advise that communicators emphasize the positive elements of the uncertainty, whenever possible, such as when it reflects a growing evidence base. Health promoters should consider the long-term outcomes of communicating uncertainty, as these may differ from the short-term outcomes. We identify knowledge gaps and areas ripe for future research.

We also show that uncertainty can often be communicated without harming trust in the communicator, and that communicators should rely on evidence-based best practices. We aim to provoke further discussion on how uncertainty should be understood and framed in health promotion efforts, guiding communicators on how to maintain public trust amid unknowns.

Keywords: *health communication, public health, uncertainty, risk, trust*

Highlights

- By leveraging research on uncertainty communication, health promoters can communicate in a manner that helps to foster trust.
- Communicators are advised to keep in mind the specific type of uncertainty they are dealing with.
- Uncertainty may have positive elements, which can be emphasized.
- Whenever possible, consider and assess long-term outcomes of communicating uncertainty.

Introduction

Health promotion guidelines are more compelling if they come from a trusted messenger.[1] Communicators can earn trust by conveying information mindfully and transparently, based on the best evidence. Yet health communicators must often address topics that inherently involve uncertainties, such as knowledge gaps or conflicting evidence. Effectively framing uncertainty without eroding trust is a significant challenge. While uncertainty was ubiquitous during the COVID-19 pandemic, it continues to affect health promotion research and guidelines in areas such as exercise, nutrition and vaccination.

The aim of this commentary is to provide insight into when uncertainty leads to trust or mis/distrust, and to provide health communicators with evidence-based approaches for conveying uncertainties in ways that cultivate trust. We emphasize that the effects of uncertainty on trust depend on various factors, including how it is communicated, messenger credibility and the type of uncertainty involved. Drawing upon previous reviews,[2] recent and relevant academic literature[3,4] and our academic and public health experiences, we offer recommendations acknowledging nuances and complexities. We highlight the limitations of previous research and suggest areas for further work.

We recommend that health communicators (1) determine the type of uncertainty involved and select appropriate communication tactics; (2) normalize uncertainty while maintaining accuracy; and (3) consider long-term outcomes of communicating uncertainty.

Best practices when communicating uncertainty

1. Determine the type of uncertainty involved and select appropriate communication tactics

Uncertainty is inherent to science and comes in many forms,[2] with each having implications for the audience's response. We discuss three types of specific categories or forms of uncertainty, and highlight links with mis/distrust and suggest areas for further research:

- Deficient uncertainty: A known knowledge gap.
- Consensus uncertainty: Disagreement among people or data sources.
- Technical uncertainty: Numeric uncertainty such as margins of error.

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Deficient uncertainty

Communicating unknowns can foster or hinder trust.[2] In this subsection, we focus on one common way of communicating knowledge gaps: hedging. In keeping with previous research, we distinguish between discourse-based hedging and lexical hedging.

Discourse-based hedging refers to acknowledging limitations or caveats, such as noting that a study result might not be reliable because of its small sample size.

In one study, college students read one of five news articles about cancer, for example, whether lycopene consumption can prevent prostate cancer.[5] The articles included high or minimal levels of discourse-based hedging, attributed to the primary or an unaffiliated researcher. When the primary scientist hedged, they—and the journalists who wrote the article—were rated as more trustworthy. Ratings of expertise were not affected. When the study was replicated with participants recruited in shopping malls reading four news articles,[6] hedging by the primary scientist was associated with higher journalist—but not scientist—credibility ratings compared with a low-uncertainty condition. Thus, when presenting research findings, hedging may enhance, or at least not reduce, trustworthiness.

Given the inconsistent effects of discourse-based hedging on audiences' perceptions of scientists, future research should explore moderating conditions, such as whether discourse-based hedging is more accepted by audiences with more formal education.[7,8]

Discourse-based hedging has also been examined in the context of COVID-19. Hedging by a scientist—including expressions of uncertainty due to limited data or other reasons affecting their estimate of the prevalence of post COVID-19 condition (long COVID)—was associated with less trust in that scientist compared with when the scientist did not hedge.[3] However, the scientist's degree of uncertainty might have been so strong that it elicited distrust; they stated that "the study result of 13% is of limited significance" [translated from German]. In addition, measures of scientist integrity, benevolence and competence were unaffected. Hedging regarding hypothetical COVID-19 vaccine side effects or efficacy has been shown to not influence trust initially, and to even buffer trust to an extent, in the face of changing evidence (see best practices recommendation 3, "Consider long-term outcomes of communicating uncertainty").[9,10] With some exceptions,[11,12] health-related discourse-based hedging does not appear to diminish trust,[13] may increase trust[14] and may be beneficial for transparency. Since research on hedging sometimes incorporates additional types of uncertainty, such as technical uncertainty,[9] future work should aim to further clarify unique effects of deficient uncertainty.

Lexical hedges include words or phrases such as "might" and "could."[5] Some studies found that lexical hedges did not affect trust in the sources that made claims about cancer, vaccines, mask-wearing (preventing coronavirus transmission) or other topics.[14-16] In another study, Durik et al. reported that colloquial lexical hedges (e.g. "sort of"), but not professional ones (e.g. "may"), were associated with more negative impressions of a communicator compared with the absence of hedges.[17] However, this was only the case among participants with lower scientific reasoning scores. Thus, for lexical hedging, words may matter—and formality in health promotion messaging might be beneficial.

Promising future research directions include clarifying the impacts of other qualities of hedges, including extremity, that is, whether hedges temper a claim or negate it altogether.

Consensus uncertainty

Consensus uncertainty is often received negatively.[2] Reading conflicting research findings about jogging or milk consumption can foster more negative attitudes toward health research.[18] Likewise, conflicting messages about whether red meat consumption causes cancer, involving disagreement among researchers or differences between findings, reduced trust in scientists compared to a consistent-findings control condition. This was pronounced when the scenario involved researcher or evidence disagreement rather than another scenario involving changing guidance from the same source.[19]

These findings suggest that health communicators might benefit from presenting a united front when there is genuine agreement. In these situations, communicators may also maintain trust by avoiding perceptions of collusion, particularly for skeptical audiences. Aklin and Urpelainen found that greater expert consensus enhanced policy support among people who trusted scientists, but reduced it among those who distrusted scientists—potentially because it implied collusion.[20] Future research may help elucidate how to emphasize consensus without the appearance of collusion.

Amid consensus uncertainty, precautionary language may sometimes enhance trust. After reading about consensus uncertainty concerning a fictitious health risk (a micro-organism in tap water), participants in a Canadian study reported marginally higher trust in the government when that government presented the situation as a potential risk and recommended precautions.[21] Any discussion of precautionary approaches can be informed by an understanding of audiences' values and costs and benefits of precautions.[22]

Technical uncertainty

Technical uncertainty is associated with positive or neutral effects on credibility and other outcomes,[2] though some negative effects have been reported.[23,24]

When describing numbers, expressing technical uncertainty in words (e.g. by saying, "There is some uncertainty around this estimate") may lead to greater distrust of the numbers and the source compared to numeric uncertainty (e.g. by providing a range) or not acknowledging uncertainty.[25,26] As with hedging, the specific wording might matter: advisers are at times perceived more negatively when they use the word "probably."[27] The effects on trust of verbalizing technical uncertainty appear to be relatively small.[25,27]

When expressing technical uncertainty using numeric ranges, providing guidance as a narrow range may be better received than if this is a wider range.[27] For example, people were more likely to rely on others' estimates (e.g. regarding calories in food items) when these were provided as low-uncertainty ranges, rather than wider ranges or point estimates.[28]

Risk presentation also affects the messenger's credibility. When presenting risks of an acne medication's side effects, the messenger was seen as less credible when presenting a range rather than a point estimate.[24] Of note, if the range was relatively narrow, credibility was spared when the messenger was a hypothetical local

primary care clinician (versus a hypothetical pharmaceutical company).[24] Exploring synergies between messenger credibility and uncertainty acknowledgement with regards to trust is another promising avenue for future research.

2. Normalize uncertainty while maintaining accuracy

Researchers have examined how to "normalize" uncertainty,[29] emphasizing that uncertainty is expected or desirable as a part of the scientific process in order to make it more acceptable. In the following subsections, we group findings based on whether this framing occurs before, during or after the communication of uncertainty.

Normalizing uncertainty before communicating uncertainty

Pre-emptively framing uncertainty positively can protect credibility. Although reminders of changes or inconsistency in COVID-19 data and guidance (e.g. about wearing masks) can diminish experts' credibility, Gretton et al. found that this may be mitigated by pre-emptively emphasizing that change is expected and indicates scientific progress.[4] Likewise, reading about the evolving nature of science resulted in people having more positive attitudes toward science when receiving conflicting messages about carbohydrate or alcohol consumption, mammography or prostate-specific antigen testing.[30] It is unclear, however, if the framing helped improve receptiveness to uncertainty or to science in general, because the study lacked a "no-uncertainty" control condition.[30] Both studies presented consensus uncertainty indirectly (e.g. via hypothetical people on social media), meaning the direct application for health communicators is unclear.

Similarly, if people were shown climate change projections as ranges after reading that science should be characterized by debate and uncertainty, they were more likely to express pro-environmental behavioural intentions than if they were first told that science seeks absolute truth.[31] This suggests that framing uncertainty as fundamental to science can make uncertainty more acceptable, though further research in health contexts is needed.

Normalizing uncertainty while communicating uncertainty

In one study, information about a hypothetical H7N3 flu outbreak and vaccine was presented to participants in Spain using certain language, uncertain language only or uncertain language paired with normalizing language (e.g. "In life, we never have perfect knowledge of any health risks…").[29] The messenger was ostensibly the director of the Ministry of Health. Trust ratings for this ministry were lower amid uncertainty, even if normalized. Although similar studies have been conducted,[11] to our knowledge they examined the existence of uncertainty rather than the communication of uncertainty by a messenger.

Research on simultaneous uncertainty-normalization is quite limited. Furthermore, pre-emptive normalization is not always possible. Additional research into the normalization of uncertainty while (or after) communicating uncertainty could be beneficial.

Normalizing uncertainty after communicating uncertainty

Lyons et al. found that providing an uncertainty-normalizing message after a change in recommended antibiotic regimens did not affect the rated credibility of medical experts or doctors.[32] However, the changing (versus consistent) guidance did not affect credibility in the first place, and the manipulation check was not significant for the brief uncertainty-normalizing intervention. As a result, we are hesitant to generalize beyond this study.

Other studies provide evidence in favour of uncertainty-normalizing messages following uncertainty communication. Flemming et al. noted that although there is often a negative association between the perceived tentativeness of findings reported in an article and that article's rated credibility, this relationship can be neutralized by subsequently sharing a message arguing for the acceptability of research results being tentative.[33] However, tentativeness would need to be experimentally manipulated to determine if it causes these effects on credibility.

In addition to examining the effects of timing of normalization, future research could clarify the roles of messengers. Normalization might be more effective if provided by a distinct source rather than by the messenger who acknowledges the specific uncertainty.

3. Consider long-term outcomes of communicating uncertainty

It is important to assess short- and long-term responses to communicating uncertainty. For example, Batteux et al. reported that communicating uncertainty about the efficacy of COVID-19 vaccines does not necessarily reduce trust initially.[10] Following evidence of lower vaccine efficacy than previously stated, trust in a government representative generally diminished—but less so if people had initially received a message that conveyed uncertainty versus one that expressed greater certainty.[10] Other research also suggests that initial uncertainty can make negative news more acceptable.[9,34] However, yet other studies indicate that a numeric estimate—uncertain or otherwise—might make bad news more palatable than an initial verbal statement (e.g. "unlikely").[35]

We are not aware of research exploring whether repeated communication of uncertainty over time affects trust, though some have proposed examining cumulative effects.[36] Such research could be valuable given that uncertainty often takes time to resolve.

Conclusion

For health communication to be transparent, mentioning uncertainty is necessary—but distrust is not. In this commentary we offer actionable strategies—categorizing uncertainty, normalizing it and considering long-term outcomes of communicating it—that health promoters can leverage to improve uncertainty communication. Applying evidence-based messaging strategies can promote trust and encourage the uptake of health promotion guidelines. Amid many unknowns, that much is certain.

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Other PHAC publications

Researchers from the Public Health Agency of Canada also contribute to work published in other journals and books. Look for the following articles published in 2025:

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