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Inside this issue

Original quantitative research

- 1** Exploring the association between the proximity to and density around schools of retailers selling IQOS products and youth use of heated tobacco products: evidence from the 2020–2021 COMPASS study
- 9** Functional difficulties in children and youth with autism spectrum disorder: analysis of the 2019 Canadian Health Survey on Children and Youth
- 21** Health care barriers and perceived mental health among adults in Canada during the COVID-19 pandemic: a population-based cross-sectional study

Release notice

- 34** *Canadian Cancer Statistics 2023*

Announcement

- 35** Call for papers: Generating stronger evidence to inform policy and practice: natural experiments on built environments, health behaviours and chronic diseases
- 37** Other PHAC publications

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Original quantitative research

Exploring the association between the proximity to and density around schools of retailers selling IQOS products and youth use of heated tobacco products: evidence from the 2020–2021 COMPASS study

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Abstract

Introduction: Heated tobacco products (HTPs) are novel tobacco products that may appeal to youth. This study explored whether HTP retailer proximity and density to secondary schools were associated with youth use of HTPs in four Canadian provinces.

Methods: An online search between November 2020 and March 2021 identified retailers selling IQOS devices and HEETS (tobacco sticks used in IQOS) within 500 m, 1000 m and 1500 m radius circular buffer zones around high schools (N = 120) participating in the COMPASS study in 2020–2021. Retailer proximity/density data were linked to cross-sectional student-level data (N = 40 636 students), and multilevel regression models examined the association between HTP retailer proximity and density and current HTP use, controlling for relevant covariates.

Results: While only 10.0% of schools had at least one retailer selling IQOS devices within 1000 m of the school, 65.0% of schools had at least one retailer selling HEETS. The school a student attended accounted for 23.7% of the variability in the likelihood of currently using an HTP. However, HTP retailer proximity to and density around schools were not significantly associated with the likelihood of students currently using HTPs.

Conclusion: While the school a student attended accounted for a significant amount of variability in HTP use, these findings suggest that students may be obtaining HTPs through other, non-retail sources. Continued monitoring is warranted as HTP use among youth may change.

Keywords: heated tobacco product, HTP, heat-not-burn product, tobacco, retailer density, retailer proximity, adolescent, IQOS

Introduction

Heated tobacco products (HTPs, or “heat-not-burn products”) heat tobacco sticks into an aerosol that the user inhales.^{1,2} HTPs differ from traditional cigarettes, which are burnt so that the user inhales tobacco smoke, and from e-cigarettes, which

heat a nicotine-containing solution into an aerosol that the user inhales.¹ IQOS is a common brand of HTP,² whereas HEETS are sticks of tobacco that are used with IQOS devices. Both can be found in specialty stores (such as IQOS’ Q-lab stores and boutiques) and non-specific stores (e.g. gas stations and convenience stores).³

Highlights

- This study is the first to explore the association between the proximity to and density of IQOS retailers to secondary schools and students’ use of heated tobacco products (HTPs).
- The school a student attended significantly affected the likelihood that they currently use HTPs.
- It is necessary to continue monitoring HTP retailer proximity to and density near schools and prevalence of HTP use among youth as HTPs become more common in Canada.

IQOS was introduced to the Canadian market in 2017⁴ and is regulated under the *Tobacco and Vaping Products Act*.⁵

Since HTPs heat rather than burn tobacco, levels of carcinogens and toxicants produced are lower than those emitted by cigarettes,⁶ which contributed to the decision made by USA to approve IQOS as a “modified risk tobacco product.”⁷ However, an experimental study showed human bronchial cell cytotoxicity levels to be lower when using HTPs compared to

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when smoking cigarettes, but higher than during e-cigarette use.² Furthermore, a systematic review suggests a positive correlation between HTP use and the incidence of respiratory complications, including airway remodelling and inflammation.⁸ Given the novelty of HTPs, research on their long-term health effects is limited.⁸

Although IQOS products were proposed as a substitute to help reduce smoking behaviours in current cigarette smokers, adolescents may use these products instead of cigarettes.^{1,9-12} While US data indicate that awareness of HTPs among youth increased between 2017 and 2020,^{1,9} ever and current use has remained low (<3%).⁹⁻¹¹ Data from the Republic of Korea also indicate that ever use of HTPs remained low (2.9%) one year after their introduction onto the market in 2017.¹² Despite a low prevalence of use, 33.0% of youth in Canada and 40.9% of youth in the USA reported being interested in trying IQOS in 2017, and 40.1% of youth in Canada and 46.1% of youth in the USA were susceptible to trying IQOS in the future.¹

The diffusion of innovation theory proposes a mechanism for adoption and increased prevalence of a new idea, product or behaviour, for example, the use of HTPs, over time; youth who use HTPs in the early stages, that is “innovators” or “early adopters,” may influence others to try the product.¹³ As more individuals try the product, its diffusion in the population grows.

Evidence indicates that students in schools with a higher concentration of tobacco retailers nearby are more likely to smoke cigarettes.¹⁴ Tobacco product retailers near secondary schools may influence adolescent smoking behaviours by offering adolescents opportunities to conveniently access products and notice tobacco product marketing strategies.¹⁴ According to a cohort study in the UK, adolescents exposed to point-of-sale displays involving tobacco products were more susceptible to smoking.¹⁵ Given this evidence for an association between exposure to tobacco product marketing and risk of future tobacco use, investigating the possible association between the density and proximity of IQOS retailers and secondary schools is warranted.

To our knowledge, only one study, conducted in Israel, has examined the density

of and proximity to schools of IQOS retailers; the authors reported an average of 1.60 retailers within a 400 m radius of schools and an average of 8.73 retailers within a 1000 m radius.¹⁶ We are not aware of any published studies that evaluate the association between IQOS retailer density and proximity to secondary schools and youth use of HTPs.

The objectives of our study were to examine whether (1) IQOS retailer proximity to schools and (2) IQOS retailer density near schools were associated with past 30-day (current) HTP use in a convenience sample of Canadian students.

Methods

Sample selection

This study used data from the 2020–2021 Cannabis, Obesity, Mental health, Physical activity, Alcohol, Smoking, and Sedentary behaviour (COMPASS) study,¹⁷ which included 53 469 students in Grades 9 through 12 (secondary I–V in Quebec) across 133 Canadian secondary schools in British Columbia (n = 14), Alberta (n = 5), Ontario (n = 51) and Quebec (n = 63).

COMPASS data are available upon reasonable request by completing a COMPASS Data Usage Application at: <https://uwaterloo.ca/compass-system/information-researchers>.

The University of Waterloo Office of Research Ethics Committee (ORE #30118) and participating school board ethics committees approved all procedures.

Student-level measures

Past 30-day (current) HTP use was assessed with a single question: “In the last 30 days, did you use any of the following? (Mark all that apply)” with one of the response options being “Heated tobacco product (a device that heats tobacco instead of burning it, such as IQOS or Heatstick).” Students who selected this response were categorized as current (past 30-day) HTP users, while those who did not were categorized as non-current HTP users.

Students also self-reported their gender (female, male, other, prefer not to answer); school grade (9, 10, 11, 12 or other, or secondary I, II, III, IV, V in Quebec), ethnicity (White, Black, Asian, Latin American/Hispanic, other, mixed); weekly spending

money (\$0, \$1–5, \$6–10, \$11–20, \$21–40, \$41–100 or >\$100); cigarette smoking behaviours (ever use and past 30-day use); and e-cigarette use behaviours (ever use and past 30-day use). Those who reported smoking in the past 30 days were considered current smokers; those who reported ever smoking but not in the past 30 days were considered ever smokers; and those who did not report ever smoking were considered never smokers. Similar definitions were used for e-cigarette use.

School-level measures

Consistent with other school-based studies,^{18,19} urbanicity was determined based on school postal codes and the classification of “rural” area and “small,” “medium” and “large urban” population centres by Statistics Canada.²⁰ Based on this classification, we classified 12 schools as “rural,” 45 as “small urban,” 10 as “medium urban” and 53 as “large urban.”

Proximity and density of retailers selling IQOS devices and HEETS

Between November 2020 and March 2021, we used the IQOS search engine (<https://ca.iqos.com/store/en/search>) to identify retailers selling (1) IQOS devices and (2) HEETS (tobacco sticks used with IQOS) located within 6 km of each secondary school participating in the COMPASS study.

We tracked each retailer’s name, address and estimated distance to the nearest school in our sample (if within 6 km of a school) on an Excel spreadsheet (Microsoft Corp., Redmond, WA, US). Using the postal codes of each school and each retailer, we geocoded each address and created circular buffer zones with 500 m, 1000 m and 1500 m radius (0.31, 0.62 and 0.93 miles, respectively) from each school using geographic information system software ArcGIS (Esri, Redlands, CA, US). A 1000 m radius circular buffer zone is believed to approximate how far students would actively commute, that is, walk or cycle, to school,²¹ and is consistent with previous literature examining the density and proximity of tobacco retailers and adolescent smoking.¹⁴ Given the lack of definite evidence in this area, we explored whether the association differed for closer (i.e. 500 m) and farther (i.e. 1500 m) distances. We used the number of retailers selling IQOS devices and HEETS within each circular buffer zone to identify the retailer

proximity/density. The retail proximity/density data for each school were linked to student-level data for each school based on a unique school code.

Analysis

Descriptive statistics identified the mean number of retailers within 500 m, 1000 m and 1500 m of each school. A null, multi-level regression model examined whether current HTP use varied across schools by calculating the intraclass correlation coefficient (ICC).

The next set of multilevel models examined whether the presence of any retailers (i.e. proximity) selling (1) IQOS devices and (2) HEETS at each distance was associated with current HTP use in separate models (2 devices × 3 distances = 6 models for proximity), while adjusting for province, school urbanicity, student-level characteristics (grade, gender, ethnicity, amount of spending money, cigarette smoking status, e-cigarette use status) and student-level clustering within schools.

Another set of multilevel models examined whether an increasing number of retailers (i.e. density) selling (1) IQOS devices and (2) HEETS at each distance was associated with current HTP use in separate models (6 models total), while adjusting for the same covariates and student-level clustering within schools.

We excluded data from 13 schools (3 in British Columbia, 1 in Alberta, 6 in Ontario and 3 in Quebec) that participated in the 2020–2021 COMPASS study but for which we did not have retailer data (n = 5639 students). Students with missing outcomes (n = 6811) or covariates (n = 383) were excluded from the analyses (representing 15.0% of the sample), leaving a final sample of 40 636 students. Students with missing outcomes tended to be male, other/mixed ethnicity and to not report their spending money; there were no significant differences in cigarette smoking or e-cigarette use status (data not shown).

Descriptive statistics and regression models were completed using statistical software

SAS, version 9.4 (SAS Institute Inc., Cary, NC, US).

Results

In our sample, 0.80% of students reported using HTPs in the last 30 days (Table 1). While the prevalence of use was low across many demographic characteristics, students in Grade 12, those who identified their gender as other or preferred not to answer, and those of other/mixed ethnicity reported higher rates of HTP use. Similarly, current smokers and current vapers also reported higher rates of HTP use.

Proximity of retailers selling IQOS devices and HEETS

The overall percentage of schools in our sample that had at least one retailer within 500 m, 1000 m and 1500 m of the school selling IQOS devices was 4.2%, 10.0% and 21.7%, respectively (Table 2). More schools had at least one retailer that sold HEETS within those distances (35.8%,

TABLE 1
Prevalence of current heated tobacco product use, overall and by demographic and behavioural characteristics, 2020–2021 COMPASS study (N = 40 636 students)

Characteristic	Did not use a heated tobacco product, % (n)	Used a heated tobacco product, % (n)	χ^2 test
Overall	99.20 (40 311)	0.80 (325)	
Grade			
9	99.13 (8645)	0.87 (76)	
10	99.21 (9076)	0.79 (72)	
11	99.17 (7504)	0.83 (63)	$\chi^2 = 35.1, p < 0.001, df = 4$
12	98.45 (3238)	1.55 (51)	
Other	99.47 (11 848)	0.53 (63)	
Gender			
Female	99.59 (21 066)	0.41 (87)	$\chi^2 = 1006.6, p < 0.001, df = 2$
Male	99.35 (17 819)	0.65 (117)	
Other / Prefer not to say	92.18 (1426)	7.82 (121)	
Ethnicity			
White	99.57 (30 733)	0.43 (133)	$\chi^2 = 220.2, p < 0.001, df = 1$
Other / Mixed	98.03 (9578)	1.97 (192)	
Cigarette smoking status			
Never smoker ^a	99.80 (33 978)	0.20 (67)	$\chi^2 = 2577.6, p < 0.001, df = 2$
Ever smoker ^b	98.94 (4592)	1.06 (49)	
Current smoker ^c	89.28 (1741)	10.72 (209)	
Vaping (e-cigarette) use status			
Never user ^d	99.82 (25 729)	0.18 (46)	$\chi^2 = 940.5, p < 0.001, df = 2$
Ever user ^e	99.83 (7742)	0.17 (13)	
Current user ^f	96.26 (6840)	3.74 (266)	

^a Respondents who did not report ever smoking.

^b Respondents who reported smoking but not in the past 30 days.

^c Respondents who reported smoking in the past 30 days.

^d Respondents who did not report ever vaping.

^e Respondents who reported vaping but not in the past 30 days.

^f Respondents who reported vaping in the past 30 days.

TABLE 2
Proximity and density of retailers selling IQOS devices and HEETS within 500 m, 1000 m and 1500 m of secondary schools, overall and by urbanicity, 2020–2021 COMPASS study (N = 120 secondary schools)

Buffer zones around school	Retailers selling IQOS devices					Retailers selling HEETS			
	Proximity, i.e. schools with ≥1 retailer, %	Density within school circular buffer zone, n			Proximity, i.e. schools with ≥1 retailer, %	Density within school circular buffer zone, n			
		Mean	Minimum	Maximum		Mean	Minimum	Maximum	
500 m radius									
Overall	4.2	0.05	0	2	35.8	0.58	0	6	
Urbanicity									
Rural	8.3	0.08	0	1	41.7	0.50	0	2	
Small urban	0.0	0.00	0	0	17.8	0.20	0	1	
Medium urban	0.0	0.00	0	0	20.0	0.20	0	1	
Large urban	7.6	0.09	0	2	52.8	1.00	0	6	
1000 m radius									
Overall	10.0	0.13	0	2	65.0	2.08	0	20	
Urbanicity									
Rural	8.3	0.17	0	2	58.3	1.17	0	4	
Small urban	0.0	0.00	0	0	53.3	0.69	0	3	
Medium urban	10.0	0.20	0	2	70.0	1.30	0	4	
Large urban	18.9	0.23	0	2	75.5	3.62	0	20	
1500 m radius									
Overall	21.7	0.30	0	4	77.5	4.00	0	33	
Urbanicity									
Rural	16.7	0.25	0	2	58.3	1.75	0	8	
Small urban	8.9	0.09	0	1	64.4	1.18	0	4	
Medium urban	20.0	0.30	0	2	80.0	2.80	0	7	
Large urban	34.0	0.49	0	4	92.5	7.21	0	33	

Note: IQOS is a common brand of heated tobacco product (HTP), whereas HEETS are sticks of tobacco that are used with IQOS devices.

65.0% and 77.5%, respectively). Not surprisingly, there tended to be a higher proximity of retailers that sold IQOS devices and HEETS in large urban areas than in small or medium urban areas.

Density of retailers selling IQOS devices and HEETS

At 0.05, 0.13 and 0.30, respectively, the average density of retailers selling IQOS devices within 500 m, 1000 m and 1500 m of each school in our sample was low (Table 2). In contrast, at 0.58, 2.08 and 4.00, respectively, the average density of retailers selling HEETS was much higher. As for the results for retailer proximity, there tended to be a higher density of retailers that sold IQOS devices and HEETS in large urban areas than in small or medium urban areas.

Multilevel model results

The null model suggests there is significant between-school variability in the likelihood of current HTP use among students [$\sigma^2_{\mu0} = 0.326$ (0.089); $p < 0.001$]; the school a student attended accounted for

approximately 23.7% of the variability in the likelihood of currently using an HTP. The school-level prevalence of HTP use ranged from 0.02% to 2.90%, and 33 schools had no students reporting HTP use (Table 2).

After controlling for relevant covariates, the proximity to schools of retailers selling IQOS devices and HEETS was not significantly associated with current HTP use (Table 3). Similarly, after controlling for relevant covariates, the density of retailers selling IQOS devices and HEETS was not significantly associated with current HTP use (Table 4).

Discussion

Our results indicate that less than 1% of students in our sample used HTPs at the time of the COMPASS survey in 2020–2021. While there was wide variability in the number of retailers selling IQOS devices and HEETS tobacco sticks near schools in our sample, and the school a student attended accounted for a significant amount of variability in HTP use, neither the proximity nor density of retailers selling IQOS devices were significantly associated with

current HTP use. Similarly, neither the proximity nor density of retailers selling HEETS were significantly associated with current HTP use.

Consistent with previous studies,^{9,10,12} few students in our sample reported currently using HTPs. Students may be unaware of HTPs due to their relative novelty. HTP use is highest among current smokers compared to non-smokers and current vapers compared to non-vapers,^{1,9,10,12} suggesting that those who use tobacco and vaping products may be more inclined to use HTPs. Taking into account the diffusion of innovation theory, students who smoke and vape may be the first to adopt a new method of inhaling nicotine.¹³ Continued research and monitoring may help identify any rapid shifts in use by youth if HTP use gains momentum in Canada.

The prevalence of current HTP use varied widely across schools in our sample. HTPs are a relatively novel product with different levels of diffusion across areas (as illustrated by the differences in the number of retailers across population centres),

TABLE 3
Association between the presence of retailers selling IQOS devices and HEETS at various distances from a school and current use of heated tobacco products, 2020–2021 COMPASS study (N = 120 secondary schools)

Selling	Distance of retailer from school	Presence of retailers	Students who used an HTP in the last 30 days, %	Adjusted odds of using an HTP, aOR (95% CI) ^a
IQOS devices	Model 1: 500 m	No	0.81	1.00
		Yes	0.66	1.17 (0.63–2.14)
	Model 2: 1000 m	No	0.81	1.00
		Yes	0.75	1.24 (0.79–1.94)
	Model 3: 1500 m	No	0.80	1.00
		Yes	0.79	0.98 (0.69–1.40)
HEETS	Model 4: 500 m	No	0.86	1.00
		Yes	0.70	0.98 (0.71–1.37)
	Model 5: 1000 m	No	0.92	1.00
		Yes	0.74	0.87 (0.64–1.18)
	Model 6: 1500 m	No	0.81	1.00
		Yes	0.80	0.95 (0.66–1.36)

Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; HTP, heated tobacco product.

Note: IQOS is a common brand of heated tobacco product (HTP), whereas HEETS are sticks of tobacco that are used with IQOS devices.

^a From separate logistic regression models examining the likelihood of using an HTP in the last 30 days (n = 325) versus not using an HTP in the last 30 days (n = 40 311) for the proximity of retailers selling IQOS devices and HEETS at each distance (i.e. 500 m, 1000 m, 1500 m), controlling for relevant factors.

which may contribute to the variability in use across schools. Since innovative technologies can diffuse and become more widespread in a population,¹³ and peers can influence tobacco use,^{22–24} the prevalence of HTP use may increase rapidly through use by a few influential students in a school. The school environment continues to be an important setting for tobacco prevention intervention, and it may be useful to target interventions to those schools at risk of experiencing a high prevalence of tobacco use.

Overall, there were more HEETS retailers than IQOS retailers: 72.5% of schools had a HEETS retailer within 1500 m compared to 16.6% with an IQOS retailer, and schools

had an average of 3.8 HEETS retailers within 1500 m of the school compared to an average of 0.1 IQOS retailers. While the average number of retailers selling IQOS and HEETS within 1000 m of each school was lower in our study than in a recent study conducted in Israel,¹⁶ the proportion of schools with at least one retailer selling IQOS devices or HEETS was similar. IQOS devices are typically sold in specialty stores such as IQOS boutiques and Q-labs, while HEETS products can be sold in non-specific stores that are more common around schools, such as convenience stores and gas stations. The lack of IQOS retailers identified near secondary schools in our sample suggests that students may find it more difficult to obtain IQOS devices than

HEETS tobacco sticks, perhaps only leaving those students who already have an IQOS device to seek out HEETS products at retailers around their school. Adolescents could also be obtaining IQOS products through online sources like the IQOS website or through social sources (e.g. family members or friends). Additional research is needed to identify how students obtain IQOS devices in order to inform future retail policies or interventions.

This cross-sectional study did not identify a significant association between HTP retailer proximity and density and current HTP use by students, despite a high number of retailers close to schools. No existing government policies in Canada regulate the

TABLE 4
Association between the density of retailers selling IQOS devices and HEETS and current use of heated tobacco products, 2020–2021 COMPASS study (N = 120 secondary schools)

Selling	Density of retailers	Adjusted odds of using an HTP, aOR (95% CI) ^a
IQOS devices	Model 7: Each unit increase within 500 m	1.17 (0.70–1.96)
	Model 8: Each unit increase within 1000 m	1.14 (0.85–1.53)
	Model 9: Each unit increase within 1500 m	0.94 (0.74–1.20)
HEETS	Model 10: Each unit increase within 500 m	1.02 (0.89–1.17)
	Model 11: Each unit increase within 1000 m	1.00 (0.96–1.05)
	Model 12: Each unit increase within 1500 m	1.00 (0.98–1.03)

Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; HTP, heated tobacco product.

Note: IQOS is a common brand of heated tobacco product, whereas HEETS are sticks of tobacco that are used with IQOS devices.

^a From separate logistic regression models examining the likelihood of using an HTP in the last 30 days (n = 325) versus not using an HTP in the last 30 days (n = 40 311) for each unit increase in the density of retailers selling IQOS devices and HEETS at each distance (i.e. 500 m, 1000 m, 1500 m), controlling for relevant factors.

proximity or density of tobacco retailers around youth-friendly environments like schools. Given that students may notice tobacco marketing in the places they frequent, such as convenience stores and gas stations near schools, and this exposure may increase the likelihood that students use tobacco products,^{14,15} policy makers should consider zoning laws that limit the number of tobacco product retailers near schools.

Strengths and limitations

To our knowledge, this study is the first to examine the association between HTP retailer proximity and density on current HTP use by adolescents. The sample included a large, diverse sample of schools across four Canadian provinces. Limitations include the focus on IQOS products, the most widely available HTP brand in Canada.

We only searched for retailers using the IQOS website and did not use search engines such as YellowPages or Google; we assumed that the IQOS website would have the most accurate listing of retailers selling their devices in order to direct potential customers to retailers. A study that compared a list of vape retailers obtained through online searches with that of a licensure database found that many confirmed vape stores identified through the online search were not on the licensure list.²⁵ This suggests that online searches may provide a more comprehensive list of retailers relative to other document sources, possibly because they can be updated more regularly.²⁵ We did not assess the accuracy of the search results either by visiting locations in person or calling retailers to confirm the products sold. Future studies could investigate the accuracy of the retailers provided by the website and whether this differs based on urbanicity.

At the time of the search, IQOS devices were relatively new to the Canadian market. As the business expands, the IQOS retailer search engine updates the number of retailers selling IQOS devices and HEETS; therefore, the total numbers of HTP retailers surrounding schools may be underestimated. Continued monitoring is warranted to evaluate how changes in retailer proximity and density are associated with changes in student behaviours.

Student data were based on self-report, which may be at risk of recall and social

desirability bias; however, the use of passive-consent protocols limit self-selection and response bias that are common in studies of substance use behaviours.²⁶

There was a high amount of missing outcome data. While there were some differences in the demographic characteristics of those with and without missing outcomes, there were no significant differences in cigarette smoking or e-cigarette use status. Given the large sample size for analysis, we believe there is sufficient statistical power to draw meaningful conclusions without data imputation.

Conclusion

This was the first study to examine the association between HTP retailer proximity and density to schools and current use of HTPs by students. While the prevalence of current HTP use was low in our sample, the majority of schools had at least one retailer selling IQOS or HEETS within 1000 m of the school and the school environment accounted for a high amount of variability in student HTP use. As there was no significant association between HTP retailer proximity/density and HTP use by students, students may be obtaining HTP products through other, non-retail sources including social sources. Additional monitoring of the distribution of HTP retailers and the prevalence of HTP use is warranted as knowledge, awareness and use of HTPs among youth may change.

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Conflicts of interest

Scott Leatherdale is one of this journal’s associate scientific editors, but has recused himself from the review process for this article.

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Authors’ contributions and statement

HM – Conceptualization, data curation, formal analysis, writing – original draft, writing – review & editing.

STL – Data curation, funding acquisition, writing – review and editing, conceptualization, investigation, methodology, project administration, resources.

AGC – Conceptualization, formal analysis, methodology, supervision, writing – review & editing.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Original quantitative research

Functional difficulties in children and youth with autism spectrum disorder: analysis of the 2019 Canadian Health Survey on Children and Youth

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Abstract

Introduction: This study examined the prevalence of functional difficulties and associated factors in Canadian children/youth aged 5 to 17 years diagnosed with autism spectrum disorder (ASD).

Methods: We analyzed data from the 2019 Canadian Health Survey on Children and Youth (CHSCY), a nationally representative survey of Canadian children/youth that used the Washington Group Short Set on Functioning (WG-SS) to evaluate functioning in six daily tasks. For each functional domain, binary outcomes were derived (no/some difficulty, a lot of difficulty/no ability). We used logistic regression to identify associations between demographic characteristics, educational experiences, and perceived mental and general health and the most common functional difficulties, namely those related to remembering/concentrating, communication and self-care. All estimates were weighted to be representative of the target population. The bootstrap method was used to calculate variance estimates.

Results: Analysis of the records of 660 children/youth with ASD revealed that the most common functional difficulties were remembering/concentrating (22%; 95% CI: 18–27), communicating (19%; 95% CI: 15–23) and self-care (13%; 95% CI: 10–17). Lower perceived mental health was associated with increased functional difficulties with remembering/concentrating. ASD diagnosis at a lower age and lower perceived general health were associated with increased functional difficulty with communication. Parental expectations for postsecondary education were associated with decreased functional difficulty for self-care.

Conclusion: One or more functional difficulties from the WG-SS was present in 39% of Canadian children/youth aged 5 to 17 years with ASD. Functional difficulties with remembering/concentrating, communication and self-care were most common.

Keywords: ASD, function, disability, adolescents, CHSCY

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impaired communication and social interaction, and restricted and repetitive

behaviours, interests and activities.¹ The term “spectrum” in ASD reflects the wide range of symptoms and varying degrees of challenges experienced by those with the disorder.^{2,3} According to the 2019 Canadian Health Survey on Children and Youth

(CHSCY), approximately 1 in 50 children/youth aged 1 to 17 years have been diagnosed with ASD.⁴ Children/youth with ASD exhibit heterogeneous communicative, social and behavioural capacities as well as diverse symptom presentations and functional abilities.⁵⁻⁷

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When assessing functional ability, the concept of a “functional difficulty” refers to difficulties with basic activities, which may affect a child’s ability to participate in their day-to-day environment if this is unaccommodated.⁸ Functioning is influenced by the interaction between individual health conditions, such as ASD, and contextual factors, such as environmental factors (e.g. social and legal structures, built environment) and personal factors (e.g. gender, social background).⁹ This definition is based on the biopsychosocial model of disability, put forward in the *International Classification of Functioning, Disability and Health* (ICF); the ICF integrates the medical model, which views disability as a feature of the person or diagnosis, and the social model, which views disability as social problem created by a lack of accommodations in the environment.⁹ Functional difficulties are not rare, but their prevalence can vary widely in different populations, including people of all ages with ASD.¹⁰ Examinations of these challenges within the ASD population are predominantly clinic-based or drawn from small, nonrepresentative samples, which limit the generalizability of the findings.

Data from the CHSCY provide a valuable resource for studying functional difficulties in children/youth aged 1 to 17 years, including those with ASD.¹¹ The CHSCY uses the Washington Group on Disability Statistics Short Set on Functioning (WG-SS) to measure functional difficulty in the general population of children/youth. Although this tool is an internationally accepted method for identifying disability in children,¹² it has not been validated specifically for children/youth with ASD. More intensive measures of functioning exist, but those developed specifically for children/youth with ASD typically require adaptive testing and are difficult to administer on a larger scale.^{13,14}

There is a lack of nationally representative knowledge about the range of functional abilities in Canadian children/youth with ASD. Identifying these functional difficulties and their associated factors can help us understand the specific day-to-day challenges faced by this population, and, subsequently, better meet their service needs. Using cross-sectional survey data from the 2019 CHSCY, the objectives of this study were to estimate the prevalence of common functional difficulties in children/youth (5–17 years) diagnosed with

ASD and explore factors associated with these difficulties.

Methods

Data

We used data from the 2019 CHSCY, a national, cross-sectional survey administered by Statistics Canada that collected health information on children/youth aged 1 to 17 years living in private dwellings in Canada’s 13 jurisdictions (response rate 52.1%).¹¹ The survey was implemented using electronic questionnaires and follow-up by phone interview between 11 February 2019 and 2 August 2019. The survey was administered to the “person most knowledgeable,” usually a parent, and for simplicity we use the term “parent.” Children/youth aged 12 to 17 years were also surveyed for select questions.

The CHSCY sampling frame was created using the Canadian Child Benefit files, which as of 31 January 2019, included 98% of the Canadian population aged 1 to 17 years in the 10 provinces and 96% in the three territories. Because of the limitations of this sampling frame, children/youth living on First Nations reserves and other Indigenous settlements in the provinces, in foster homes and in institutions are excluded from the CHSCY data and therefore from our analysis.¹¹ Age stratification and geographical sub-stratification were used to create a representative sample of the Canadian children/youth population.

Statistics Canada selected 91 796 children/youth and received 47 871 responses. Response rates were lower in the Northwest Territories, in Saskatchewan and in the 12- to 17-year age group. Most nonresponses were due to refusal or unsuccessful contact attempts.¹¹ Sampling weights were calculated to account for out-of-scope units, nonresponse, extreme weight trimming and calibration-to-known population totals. For more information on the sampling and weighting procedures, refer to the CHSCY User Guide.¹¹

The 2019 CHSCY dataset included 819 records of individuals aged 1 to 17 years with a self-reported ASD diagnosis. Of those 819 records, 660, representing 112 966 children/youth, were 5 years of age and older; we used this sample for our analysis. The most common reasons for record exclusion from our analysis was that the respondent

reported no ASD diagnosis (97.9% of records), information on ASD diagnosis was missing (0.02% of records) or the child was 4 years old or younger (19.4% of records for children with ASD).

Outcome measures

The WG-SS functional difficulty measurement set is an internationally accepted method for identifying disability in children.¹² It was developed to measure disability in a culturally neutral and globally standardized way. The United Nations recommends this tool to assess progress towards equal treatment of people with disabilities. This task is part of the United Nations Convention on the Rights of Persons with Disabilities.¹⁵

Using this framework, we can measure the extent of disability in a way that allows comparison with data for other disabilities and from other jurisdictions. The WG-SS consists of six questions that assess a person’s ability to function in six basic activity domains: communicating, hearing, seeing, walking, remembering/concentrating and self-care (Table 1).¹⁵ For each of the WG-SS questions, the respondent is asked if they have no difficulty, some difficulty, a lot of difficulty or a complete inability (“cannot do at all”) to perform the task.

To better capture disability in children/youth, the WG-SS was adapted into a module specifically aimed at children aged 2 to 4 years and children/youth aged 5 to 17 years. This tool has been iteratively developed and validated using standard Washington Group validation procedures.¹² The tool was not developed or tested specifically for children/youth with ASD.

Our data analyses focussed on remembering/concentrating, communicating and self-care functional difficulties because a previous analysis of the CHSCY dataset¹⁶ found these to be the most common among children/youth with ASD. Since remembering/concentrating and self-care functional difficulties were only defined for children/youth older than 4 years, our analysis was restricted to the population aged 5 to 17 years. Children/youth were considered to have functional difficulty when the respondent indicated that they had a lot of difficulty performing the task or were unable to perform the task. See Table 1 for the definitions for each functional difficulty.

TABLE 1
Washington Group on Disability Statistics Short Set on Functioning (WG-SS) questions that assess a person's ability to function in six basic activity domains

Domain	Question	Definition for children/youth aged 5–17 years ^a
Memory/concentration	Do you have difficulty remembering or concentrating?	If a parent reported that their child/youth had a lot of difficulty remembering things compared to other children/youth of the same age, or could not do it at all; or if a parent reported that their child/youth had a lot of difficulty concentrating on an activity that they enjoyed, or could not do it at all.
Communicating	Using your usual language, do you have difficulty communicating, for example, understanding or being understood?	If a parent reported that their child/youth had a lot of difficulty being understood by people inside or outside of the household when speaking, or could not do it at all.
Self-care	Do you have difficulty with self-care, such as washing all over or dressing?	If a parent reported that their child/youth had difficulty with self-care such as feeding or dressing themselves.
Walking	Do you have difficulty walking or climbing steps?	If a child/youth had an assistive device but their parent reported that their child/youth had a lot of difficulty walking 100 m or 500 m without their device or could not do it at all; or if a child/youth did not have an assistive device but their parent reported the same difficulty compared to children/youth the same age.
Seeing	Do you have difficulty seeing, even if wearing glasses?	If a parent reported that their child/youth wore corrective lenses but had a lot of difficulty seeing with their lenses or could not do it at all; or their child/youth did not wear corrective lenses but had the same difficulty.
Hearing	Do you have difficulty hearing, even if using a hearing aid?	If a child/youth used a hearing aid and their parent reported that the child/youth had a lot of difficulty hearing sounds like people's voices or music with their aid, or could not do it at all; or if a child/youth did not use a hearing aid, and their parent reported the same difficulty.

Note: The survey was administered to the “person most knowledgeable,” who was usually a parent. For the sake of simplicity, we use the term “parent.”

^a Children/youth aged 12 to 17 years as well as their parents were surveyed for select questions.

Factors associated with functional difficulties

Potential associated factors were chosen from among those available in the CHSCY dataset based on a literature review targeting factors associated with daily function among children/youth and adults with ASD.^{16–20} We included sociodemographic variables such as sex, location of birth, racial/ethnic minority status, age, household size and household income. We also included diagnoses of neurobehavioural and mental health disorders such as attention deficit hyperactivity disorder (ADHD), anxiety disorders, mood disorders and learning disabilities. Because these disorders are characterized by inattention, impaired concentration and difficulty processing information, they are potentially associated with rates of functional difficulties.¹

We also included academic accommodations provided to the child at school and parental expectations for the child's future educational attainments because of the importance of academic experiences for children/youth with ASD. It is possible that children/youth with ASD with increased functional difficulties require additional academic accommodations, for example, different curricula or ways to access academic content.²¹ Challenges with communication combined with restricted interests

and repetitive behaviours can limit the academic achievements of children/youth with ASD, and academic skills are essential for succeeding after adolescence.^{22,23} Youth aged 12 to 17 years reported their own academic accommodations, and parents reported for children aged 5 to 11 years.

We included age at time of ASD diagnosis because previous studies have found that age at diagnosis differs with symptom severity.^{24–26} Finally, we also included two health indicators, perceived general health and perceived mental health, because of the relationship between ASD and overall health outcomes.^{27,28}

Youth aged 12 years and older rated their own general and mental health; for children/youth where a self-rating was not available, we used the rating provided by the parent. Unless otherwise specified, all other variables used in our analyses were reported by the parent.

Data analysis

Following the analytical guidelines and recommendations of the WG-SS, each WG-SS functional difficulty was represented as a binary variable, where 0 represented no or some difficulty and 1 represented a lot of difficulty or no ability.^{29,30}

We used chi-square or independent two-sample Student *t* test to compare cohort characteristics for children/youth who did and did not have remembering/concentrating, communicating and self-care functional difficulties. Multivariable logistic regression analyses were performed to understand associations between predictor variables and remembering/concentrating, communicating and self-care functional difficulties. All factors potentially associated with the outcome were included in the logistic regression.

Valid skips, where a question did not apply to the respondent and therefore was not asked, were excluded from the analyses, as were missing values. The potentially associated factors had 0% to 4% missing values, and the WG-SS variables had 0% to 1.5% (unweighted).

All estimates were weighted to be representative of the target population using sampling weights provided by Statistics Canada. Variance estimates, including 95% confidence intervals (CIs) and coefficients of variation (CVs), were determined using balanced repeated replication to account for the complex survey design. Model assumptions were met, including linearity, multicollinearity and a lack of outlier influence on the significance of the results.

The observations are assumed to be independent, given the Statistics Canada sample frame definition.

An alpha criterion of 0.05 was used to determine statistical significance. Estimates with a CV of less than 15.0% were considered reliable for general use, estimates with CVs between 15.0% and 35.0% were accompanied with a warning of high sampling variability, and estimates with CVs higher than 35.0% were deemed unreliable. We conducted data cleaning steps in statistical package R version 4.1.1 (R Foundation for Statistical Computing, Vienna, AT) and statistical analyses using SAS version 9.4 (SAS Institute Inc., Cary, NC, US).

Results

Cohort characteristics

In this cohort of children/youth with an ASD diagnosis ($n_{\text{unweighted}} = 660$, $n_{\text{weighted}} = 112\,966$), 80.5% were male, 91.4% were born in Canada and 76.1% were White (Table 2). The median household size where the child/youth resided was 3.6 people, and the median household income was \$79 770.

The median age at the time of the survey was 9.4 years and at time of ASD diagnosis was 4.3 years. More than one-third (40.6%) of the children/youth also had an ADHD diagnosis, while 22.5% were diagnosed with anxiety disorders and 6% with mood disorders (note: high sampling variability, i.e. CV between 15.0% and 25.0%). Almost half (48.1%) had a learning disability.

Of those children/youth who attended school, 78.9% had academic accommodations and 6.8% of respondents were unsure if the child had accommodations (data not shown). In the case of 69.9% of the children/youth, their parents expected future postsecondary education.

Proportion of different functional difficulties

Of all children/youth aged 5 to 17 years with an ASD diagnosis, 22.2% (95% CI: 17.9–26.5) reported functional difficulty with remembering/concentrating, 18.9% (95% CI: 14.7–23.0) with communicating and 13.3% (95% CI: 9.7–16.9) with self-care (Table 3). Functional difficulties with walking, seeing and hearing were less common.

TABLE 2
Cohort characteristics of children/youth aged 5 to 17 years with an ASD diagnosis,^a Canada, 2019

Characteristics	
Demographic characteristics	
Male sex, % (95% CL)	80.5 (76.1, 84.8)
Median age (Q1, Q3), years	9.4 (6.8, 13.4)
White, % (95% CL) ^b	76.1 (71.4, 80.7)
Born in Canada, % (95% CL)	91.4 (87.8, 95)
Median income (Q1, Q3), CAD	79 770.0 (42 314.0, 118 485.0)
Median number of people in the household (Q1, Q3), n	3.6 (3.0, 4.4)
Median age at ASD diagnosis (Q1, Q3), years	4.3 (2.6, 6.9)
Comorbid diagnoses, % (95% CL)	
ADHD	40.6 (35.4, 45.7)
Anxiety	22.5 (18.1, 27.0)
Mood disorder	6.0 (4.0, 7.9) ^c
Learning disability	48.1 (42.8, 53.4)
Education, % (95% CL)	
Had school accommodations ^d	78.9 (74.2, 83.6)
Expected postsecondary education	69.9 (64.9, 75.0)
Health status, % (95% CL)	
Perceived general health: excellent–good	88.8 (85.5, 92.1)
Perceived mental health: excellent–good	75.7 (71.3, 80.1)

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; CAD, Canadian dollar; CL, confidence limits; Q1, first quartile; Q3, third quartile.

^a $n_{\text{unweighted}} = 660$, $n_{\text{weighted}} = 112\,966$.

^b Reported population group White. Survey questionnaire choices were White, South Asian (e.g. East Indian, Pakistani, Sri Lankan), Chinese, Black, Filipino, Arab, Latin American, Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai), West Asian (e.g. Iranian, Afghan), Korean, Japanese or Other.

^c High sampling variability (coefficient of variation 15.0%–25.0%).

^d Determined based on the child's responses, if available, and the parent's responses if not.

Functional difficulty with remembering/concentrating

Children/youth with ASD and functional difficulties with remembering/concentrating ($n_{\text{unweighted}} = 650$, $n_{\text{weighted}} = 112\,037$) were more likely to have a comorbid ADHD diagnosis (59.8% versus 35.4%, $p < 0.001$) and a learning disability (70.0% versus 42.1%, $p < 0.001$), and less likely to have a parental expectation of postsecondary education (54.3% versus 74.5%, $p < 0.001$) and good-to-excellent perceived general health (78% versus 91.9%, $p < 0.001$) and mental health (56.4% versus 80.9%, $p < 0.001$), compared to those without this functional difficulty (Table 4).

Having a comorbid ADHD diagnosis (odds ratio [OR] = 3.0; 95% CI: 1.5–5.9), learning disability (OR = 3.2; 95% CI: 1.5–6.7) and fair-to-poor perceived mental health (OR = 2.5; 95% CI: 1.2–5.2) were associated

with higher odds of functional difficulty with remembering/concentrating among children/youth with ASD (Table 5).

Functional difficulty with communicating

Children/youth with ASD and functional difficulties with communicating ($n_{\text{unweighted}} = 654$, $n_{\text{weighted}} = 112\,366$) were more likely to have a learning disability (63.2% versus 44.8%; $p < 0.01$) and less likely to be White (63.8% versus 78.7%; $p < 0.01$), have a parental expectation of postsecondary education (51.1% versus 73.8%; $p < 0.001$) and report good-to-excellent perceived general health (74.3% versus 92.1%; $p < 0.001$) and mental health (58.1% versus 79.9%; $p < 0.001$), compared to those without this functional difficulty with communicating (Table 6).

Older age at time of survey (OR = 0.8; 95% CI: 0.6–0.9) and at diagnosis (OR = 0.8;

TABLE 3
Percentage of functional difficulties in children/youth aged 5–17 years with an ASD diagnosis, Canada, 2019

Domain	Prevalence, % (95% CL)
Memory / concentration	22.2 (17.9, 26.5)
Communicating	18.9 (14.7, 23.0)
Self-care	13.3 (9.7, 16.9)
Walking	6.0 (3.7, 8.3) ^c
Seeing	2.5 (0.8, 4.2) ^e
Hearing	0.2 (–0.1, 0.4) ^e

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: ASD, autism spectrum disorder; CL, confidence limits.

^c High sampling variability (coefficient of variation 15.0%–25.0%).

^e Unreliable estimate due to high sampling variability (coefficient of variation >35%).

TABLE 4
Significance testing for associated factors in children/youth aged 5–17 years with an ASD diagnosis, with and without remembering/concentrating functional difficulty,^a Canada, 2019

Factor	Remembering / concentrating with difficulty	Remembering / concentrating without difficulty
Demographic characteristics		
Male sex, % (95% CL)	75.4 (65.8, 85.1)	81.7 (76.8, 86.6)
Median age (Q1, Q3), years	9.3 (6.8, 12.6)	9.5 (6.8, 13.7)
White, % (95% CL) ^b	72.4 (62.1, 82.7)	77.1 (72.0, 82.1)
Born in Canada, % (95% CL)	89.5 (79.9, 99.0)	91.8 (88.1, 95.6)
Median income (Q1, Q3), CAD	85 468.0 (33 592.0, 102 190.0)	79 792.0 (44 794.0, 121 569.0)
Median number of people in the household (Q1, Q3), n	3.7 (3.2, 4.7)	3.6 (2.9, 4.3)
Median age at ASD diagnosis (Q1, Q3), years	4.3 (2.4, 6.8)	4.3 (2.7, 6.9)
Comorbid diagnoses, % (95% CL)		
ADHD ^{***}	59.8 (49.4, 70.1)	35.4 (29.6, 41.3)
Anxiety	25.7 (15.7, 35.7) ^c	21.8 (16.7, 26.8)
Mood disorder [*]	10.4 (4.8, 16) ^b	4.7 (2.8, 6.7) ^c
Learning disability ^{***}	70.0 (60.1, 80)	42.1 (36.0, 48.2)
Education, % (95% CL)		
Had school accommodations ^c	87.5 (79.6, 95.3)	76.5 (70.9, 82.0)
Expected postsecondary education ^{***}	54.3 (43.0, 65.5)	74.5 (69.0, 80.1)
Health status, % (95% CL)		
Perceived general health: excellent–good ^{***}	78.0 (69.1, 87.0)	91.9 (88.7, 95.1)
Perceived mental health: excellent–good ^{***}	56.4 (45.5, 67.4)	80.9 (76.3, 85.6)

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; CL, confidence limits; Q1, first quartile; Q3, third quartile.

^a $n_{\text{unweighted}} = 650$, $n_{\text{weighted}} = 112\,037$.

^b Reported population group White. Survey questionnaire choices were White, South Asian (e.g. East Indian, Pakistani, Sri Lankan), Chinese, Black, Filipino, Arab, Latin American, Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai), West Asian (e.g. Iranian, Afghan), Korean, Japanese or Other.

^c High sampling variability (coefficient of variation 15.0%–25.0%).

^d High sampling variability (coefficient of variation 25.0%–35.0%).

^e Determined using the child's responses, if available, and the parent's responses if not.

^{*} $p < 0.05$.

^{**} $p < 0.01$.

^{***} $p < 0.001$.

95% CI: 0.6–0.9) were associated with lower odds of functional difficulty with communicating, and fair-to-poor perceived general health (OR = 4.4; 95% CI: 1.6–11.8) was associated with higher odds of functional difficulty (Table 5).

Functional difficulty with self-care

Children/youth with ASD and functional difficulties with self-care ($n_{\text{unweighted}} = 656$; $n_{\text{weighted}} = 112\,752$) were more likely, compared to those who did not have difficulties with self-care, to have a learning disability (62.0% versus 46.0%; $p < 0.05$) and less likely to be male (69.6% versus 82.1%; $p < 0.05$), have parental expectations of postsecondary education (44.5% versus 73.5%; $p < 0.001$) and report good-to-excellent perceived general health (77.5% versus 90.6%; $p < 0.01$) and mental health (59.7% versus 78.0%; $p < 0.01$) (Table 7).

Increased age (OR = 0.8; 95% CI: 0.7–0.97) and higher educational expectations (OR = 0.3; 95% CI: 0.1–0.8) were associated with lower odds of functional difficulty with self-care (Table 5).

Discussion

Overall findings

Our study investigated the prevalence, at the national level, of functional difficulties in Canadian children/youth aged 5 to 17 years diagnosed with ASD, focussing on difficulties with remembering/concentrating, communicating and self-care. We found that functional difficulties with remembering/concentrating (22.2%), communicating (18.9%) and self-care (13.3%) were the most common in this population. These rates demonstrate that children/youth with ASD share a diagnosis, but not necessarily the same functional abilities, suggesting that different functional ability profiles may be important for service delivery, clinical care and reporting.

Three out of five children/youth with ASD were found to have none of the functional difficulties included in the WG-SS. Even the most prevalent functional difficulty, remembering/concentrating, was only present in less than one in four of the children/youth with ASD. This indicates that having an ASD diagnosis does not directly translate to functional difficulties completing daily tasks, which supports previous research suggesting that adaptive functioning as well as symptom severity must

TABLE 5
Results for multivariable logistic regression models of functional difficulties with communicating, remembering/concentrating and self-care among children/youth aged 5–17 years with an ASD diagnosis, Canada, 2019

Factor	Remembering / concentrating (n _{unweighted} = 609), aOR (95% CL)	Communicating (n _{unweighted} = 612), OR (95% CL)	Self-care (n _{unweighted} = 614), aOR (95% CL)
Demographic characteristics			
Female vs. male sex	1.3 (0.6, 2.7)	1.2 (0.4, 3.8)	1.6 (0.6, 4.6)
Age at time of survey ^a	1.0 (0.9, 1.1)	0.8 (0.6, 0.9)**	0.8 (0.7, 0.97)*
Non-White vs. White	1.0 (0.4, 2.4)	1.4 (0.6, 3.4)	1.6 (0.6, 4.7)
Other place of birth vs. Canada	1.3 (0.3, 5.8)	1.4 (0.1, 15.6)	0.6 (0, 50.8)
Household income ^a	1.0 (1.0, 1.0)	1.0 (1.0, 1.0)	1.0 (1.0, 1.0)
Household size ^a	1.2 (0.9, 1.6)	1.3 (0.9, 1.9)	1.1 (0.8, 1.6)
Age at diagnosis ^a	0.9 (0.8, 1.1)	0.8 (0.6, 0.9)**	0.8 (0.7, 1.0)
Comorbid diagnoses			
ADHD: yes vs. no	3.0 (1.5, 5.9)**	1.0 (0.4, 2.6)	1.3 (0.5, 3.9)
Anxiety: yes vs. no	0.7 (0.2, 1.8)	0.5 (0.1, 2.8)	0.5 (0, 5.8)
Learning disability: yes vs. no	3.2 (1.5, 6.7)**	2.4 (1.0, 5.6)	2.0 (0.9, 4.4)
Mood disorder: yes vs. no	1.7 (0.4, 7.4)	3.3 (0.3, 33.6)	4.0 (0.3, 59.3)
Education			
Educational accommodations: don't know vs. no	3.3 (0.3, 32.3)	0.6 (0, 115.8)	2.6 (0, 147.5)
Educational accommodations: yes vs. no	3.7 (0.7, 20.0)	0.9 (0.2, 4.1)	0.7 (0, 12.1)
Expected education: postsecondary vs. other	0.7 (0.4, 1.4)	0.4 (0.1, 1.1)	0.3 (0.1, 0.8)*
Health status			
Fair–poor vs. excellent–good perceived general health	2.2 (0.9, 5.6)	4.4 (1.6, 11.8)**	2.6 (0.8, 8.1)
Fair–poor vs. excellent–good perceived mental health	2.5 (1.2, 5.2)*	2.2 (0.9, 5.2)	1.8 (0.7, 5.0)

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: aOR, adjusted odds ratio; ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; CL, confidence limits.

^a Expressed as change in odds for a one-unit increase in the continuous variable.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

be considered when studying developmental trajectories for children/youth with ASD.³¹

Remembering/concentrating

The finding that difficulties with memory and concentration are prevalent among children/youth with ASD is noteworthy, as these challenges are not typically considered core features of ASD. Previous research has reported higher prevalence of executive functioning difficulties and unique patterns of memory functioning among individuals with ASD.^{32–34} These findings suggest that executive function may be an important intervention target for children/youth with ASD. However, we also found that ADHD and learning disability diagnoses were associated with functional difficulties with remembering/concentrating. Both comorbidities are prevalent among children with ASD.^{35,36} The association of these comorbid characteristics with remembering/

concentrating functional difficulty is difficult to disentangle because of our cross-sectional study design (see the “Limitations” section).

We found that perceived mental health was associated with functional difficulties with remembering/concentrating, after controlling for comorbid diagnoses and other individual characteristics. An individual's functional capacity may influence the relationship between ASD symptoms and mental health; specifically, deficits in executive functioning, including working memory and cognitive flexibility, may exacerbate the mental health challenges of individuals with ASD. Prior research has proposed executive functioning skills as a potential pathway through which ASD symptoms in middle childhood are linked to mental health outcomes.^{37,38} These cross-sectional findings would be important for

developing intervention programs to address challenges with memory and concentration. Incorporating strategies to improve executive functioning and memory skills within comprehensive intervention plans may contribute to better cognitive, adaptive, and mental health outcomes for children/youth with ASD.^{39,40}

Communicating

The high prevalence of communication difficulties (1 in 5) observed in our study aligns with expectations, given that social and communication deficits characterize ASD.^{16,41} Communication difficulties often present significant barriers to social interaction and academic success for individuals with ASD,^{42,43} and interventions targeting communication skills are frequently prioritized as the first educational goal for ASD programs.^{44,45}

TABLE 6
Significance testing for associated factors among children/youth aged 5–17 years with an ASD diagnosis, with and without communicating functional difficulty,^a Canada, 2019

Factor	Communicating with difficulty	Communicating without difficulty
Demographic characteristics		
Male sex, % (95% CL)	74.0 (62.8, 85.1)	82.2 (77.6, 86.9)
Median age (Q1, Q3), years	7.1 (5.4, 8.9)	10.2 (7.5, 14.0)
White, % (95% CL) ^{b,**}	63.8 (52.9, 74.7)	78.7 (73.6, 83.8)
Born in Canada, % (95% CL)	95.3 (89.6, 100.9)	90.4 (86.3, 94.6)
Median income (Q1, Q3), CAD	63 099.0 (31 903.0, 99 511.0)	80 952.0 (47 976.0, 119 575.0)
Median number of people in the household (Q1, Q3), n	3.7 (3.0, 4.7)	3.6 (3.0, 4.3)
Median age at diagnosis (Q1, Q3), years	2.9 (2.0, 4.3)	4.7 (2.8, 7.6)
Comorbid diagnoses, % (95% CL)		
ADHD	36.0 (24.4, 47.6) ^c	41.9 (36.0, 47.8)
Anxiety	19.0 (8.9, 29.1) ^d	23.1 (18.1, 28.1)
Mood disorder	7.9 (1.7, 14.1) ^e	5.5 (3.6, 7.5) ^c
Learning disability ^{**}	63.2 (52.4, 74.1)	44.8 (39.0, 50.5)
Education, % (95% CL)		
Had school accommodations ^f	86.7 (75.6, 97.9)	77.2 (72.0, 82.4)
Expected postsecondary education ^{***}	51.1 (38.5, 63.8)	73.8 (68.2, 79.3)
Health status, % (95% CL)		
Perceived general health: excellent–good ^{***}	74.3 (63.8, 84.8)	92.1 (89.0, 95.2)
Perceived mental health: excellent–good ^{***}	58.1 (46.1, 70.1)	79.9 (75.3, 84.5)

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; CL, confidence limits; Q1, first quartile; Q3, third quartile.

^a $n_{\text{unweighted}} = 654$, $n_{\text{weighted}} = 112\,366$.

^b Reported population group White. Survey questionnaire choices were White, South Asian (e.g. East Indian, Pakistani, Sri Lankan), Chinese, Black, Filipino, Arab, Latin American, Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai), West Asian (e.g. Iranian, Afghan), Korean, Japanese or Other.

^c High sampling variability (coefficient of variation 15.0%–25.0%).

^d High sampling variability (coefficient of variation 25.0%–35.0%).

^e Unreliable estimate due to high sampling variability (coefficient of variation >35%).

^f Determined using the child's responses, if available, and the parent's responses if not.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

We found an association between ASD diagnosis at an older age and decreased odds of functional communication difficulties. This may seem counterintuitive, given that early intervention has been shown to improve communication skills in children/youth with ASD,^{46–48} and early diagnosis makes early intervention possible. However, it is imperative to distinguish between the causal relationships: more severe symptoms or functional difficulties may precipitate an earlier diagnosis. Earlier diagnosis of ASD has previously been associated with delays in social communication or the presence of an intellectual disability.³¹

Perceived general health was found to be strongly associated with functional difficulties

with communication. Communication skills play a role in an individual's ability to express their health care needs; in those with ASD, communication skills are a significant factor in successful health care interactions.⁴⁹ However, it is essential to note that when perceived health is based on a parent's perception, it may be influenced by the child's inability to communicate effectively. Given the cross-sectional design, there is potential for bidirectional influences and confounding causes between perceived health and communication ability, particularly in this study. Further research using longitudinal data or experimental designs may help clarify these relationships and inform intervention strategies to improve communication and

health care outcomes for individuals with ASD.

Self-care

When analyzing self-care functional difficulties, it is important to consider sensory issues, which are a common aspect of how individuals with ASD process and respond to sensory stimuli in their environments.⁵⁰ These sensory challenges can contribute to difficulties with self-care activities, such as feeding and dressing,⁵¹ and addressing sensory needs in intervention programs designed for individuals with ASD is crucial to their overall development and well-being.⁵² By targeting and ameliorating sensory challenges, sensory-based interventions can enhance individuals'

TABLE 7
Significance testing for associated factors in children/youth aged 5–17 years with an ASD diagnosis, with and without self-care functional difficulty,^a Canada, 2019

Factor	Self-care with difficulty	Self-care without difficulty
Demographic characteristics		
Male sex, % (95% CL) [*]	69.6 (56.4, 82.9)	82.1 (77.5, 86.7)
Median age (Q1, Q3), years	7.6 (5.3, 9.6)	9.8 (7.1, 13.8)
White, % (95% CL) ^b	64.8 (51.1, 78.4)	77.7 (72.9, 82.6)
Born in Canada, % (95% CL)	96.6 (90.9, 102.3)	90.6 (86.5, 94.6)
Median income (Q1, Q3), CAD	56 012.0 (29 214.0, 99 311.0)	82 284.0 (47 051.0, 119 074.0)
Median number of people in the household (Q1, Q3), n	3.8 (2.9, 4.9)	3.6 (3.0, 4.3)
Median age at diagnosis (Q1, Q3), years	3.1 (1.8, 5.1)	4.5 (2.7, 7.3)
Comorbid diagnoses, % (95% CL)		
ADHD	41.5 (26.8, 56.1) ^c	40.5 (35.0, 46.0)
Anxiety	23.6 (10.9, 36.4) ^d	22.4 (17.7, 27.0)
Mood disorder	10.6 (2.7, 18.4) ^e	5.2 (3.4, 7.1) ^c
Learning disability [*]	62.0 (48.1, 75.9)	46.0 (40.4, 51.5)
Education, % (95% CL)		
Had school accommodations ^f	81.2 (66.5, 95.9)	78.6 (73.6, 83.5)
Expected postsecondary education ^{***}	44.5 (29.8, 59.3)	73.5 (68.2, 78.7)
Health status, % (95% CL)		
Perceived general health: excellent–good ^{**}	77.5 (66.2, 88.7)	90.6 (87.2, 94)
Perceived mental health: excellent–good ^{**}	59.7 (45.9, 73.5)	78.0 (73.3, 82.7)

Source: 2019 Canadian Health Survey on Children and Youth.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; CL, confidence limits; Q1, first quartile; Q3, third quartile.

^a $n_{\text{unweighted}} = 656$; $n_{\text{weighted}} = 112\,752$.

^b Reported population group White. Survey questionnaire choices were White, South Asian (e.g. East Indian, Pakistani, Sri Lankan), Chinese, Black, Filipino, Arab, Latin American, Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai), West Asian (e.g. Iranian, Afghan), Korean, Japanese or Other.

^c High sampling variability (coefficient of variation 15.0%–25.0%).

^d High sampling variability (coefficient of variation 25.0%–35.0%).

^e Unreliable estimate due to high sampling variability (coefficient of variation >35%).

^f Determined using the child's responses, if available, and the parent's responses if not.

^{*} $p < 0.05$.

^{**} $p < 0.01$.

^{***} $p < 0.001$.

ability to engage in self-care activities, thereby promoting greater independence and improved quality of life in children/youth with ASD.⁵³

We also found that functional difficulties with self-care were associated with lower parental expectations for educational attainment. Although self-care activities such as feeding and dressing may not directly influence academic achievement, providing support beyond academic accommodations may increase the likelihood of success for planning to attend postsecondary education.⁵⁴ Intervention programs can better equip children/youth with ASD for a successful transition to higher education by addressing sensory challenges and self-care difficulties and

promoting more favourable long-term outcomes.

Strengths and limitations

Our study had several strengths. First, it was based on a dataset that, using sampling weights, closely represented Canadian children/youth aged 5 to 17 years living in private dwellings. Data from the CHSCY are nationally representative, providing greater coverage than previous geographically limited clinical studies. Second, there were few missing answers for individual questions, and sample weights were used to compensate for differences in response rates.¹¹

Third, using the WG-SS allows for transferability of our results and for comparisons

to other countries, disabilities and age groups. Fourth, by avoiding technical terms these functional difficulty measures were designed to be self-reported, making the WG-SS framework well-suited to survey data. In addition, the WG-SS questions are not specific to ASD, which means no assumptions regarding which difficulties might be the most common were made before data analysis.

Our study also had several limitations. First, the CHSCY is cross-sectional, which does not permit causal inferences. This limitation is important, especially when interpreting the relationship between functional difficulties with communicating and early diagnosis and discerning potential bidirectional associations. Longitudinal data

collection could allow for future studies examining causality and influence.

Second, children/youth living on First Nations reserves and other Indigenous settlements in the provinces and in foster homes as well as institutions are excluded from the CHSCY sample, limiting the generalizability of the findings to all Canadian children/youth with ASD. Third, we observed high variability (CV > 15%) in some estimates due to a relatively small number of sampled individuals. This high variability reduces the utility of some descriptive statistics.

Fourth, the study relied on the parent's perception of a child's difficulty, which cultural factors may influence.⁵⁵ This reliance on parent/self-report could lead to results distorted by respondent bias or incorrect knowledge. Fifth, there is no formal validation of the ASD diagnosis that forms the basis for the studied subgroup. Sixth, the study can only claim to look at children/youth with an ASD diagnoses, not all children/youth with ASD, and the ability and inclination to access diagnosis are not evenly distributed.⁵⁶

Seventh, while the WG-SS is broad, it does not include representations of all types of difficulty associated with disability. For example, symptoms of mental illnesses are not well-captured.⁵⁷ Some of the WG-SS short-set domains are related to core indicators of ASD (e.g. communicating), but others are not. Common functional difficulties for children/youth with ASD, including social interaction and controlling behaviour, are not part of the WG-SS. Thus, this study does not comprehensively cover all possible difficulties with functioning—only the six in the WG-SS, with a focus on remembering/concentrating, communicating and self-care. Further, results should be interpreted with caution due to the lack of WG-SS validation specifically for children/youth with ASD. Future development of a survey-compatible measurement tool specific to children/youth with ASD would allow for more sophisticated analysis of these children/youth's difficulties.

Eighth, our cohort does not include children younger than 5 years who may have a higher prevalence of these functional difficulties given more severe symptoms are often associated with an earlier ASD diagnosis.

Finally, the COVID-19 pandemic may have affected the day-to-day functioning and health of children/youth with ASD. As such, the estimates provided here may not reflect the current rates of functional difficulties. We aim to update these estimates once the next cycle of CHSCY is released, in summer 2024.⁵⁸

Conclusion

Our study highlights the variable prevalence of certain functional difficulties in Canadian children/youth aged 5 to 17 diagnosed with ASD and identifies important factors associated with these functional difficulties in this population. Together, these findings suggest that an ASD diagnosis does not necessarily mean a child/youth will experience functional difficulties and emphasize the need for targeted and personalized intervention programs to address challenges.

Our findings are only a first step towards understanding the specific challenges that children/youth with ASD face: more specialized measurement tools and longitudinal data collection are required to understand the full range of functional abilities and the underlying mechanisms involved.

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Conflicts of interest

None.

Authors' contributions and statement

AF – Methodology, formal analysis, interpretation of the results, writing – original draft, writing – review and editing

AA – Methodology, formal analysis, interpretation of the results, writing – original draft, writing – review and editing

SO – Conceptualization, methodology, writing – review and editing

SP – Conceptualization, methodology, writing – review and editing

SG – Writing – review and editing

JYC – Writing – review and editing

PM – Writing – review and editing

RE – Conceptualization, project administration, methodology, supervision, writing – review and editing

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Original quantitative research

Health care barriers and perceived mental health among adults in Canada during the COVID-19 pandemic: a population-based cross-sectional study

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Abstract

Introduction: The perceived mental health of individuals in Canada who faced health care barriers during the COVID-19 pandemic is underexplored.

Methods: We analyzed data collected March to June 2021 from adults who reported needing health care services within the past 12 months in the Survey on Access to Health Care and Pharmaceuticals during the Pandemic. Unadjusted and adjusted logistic regression analyses examined the associations between health care barriers (appointment scheduling problems, delaying contacting health care) and high self-rated mental health and perceived worsening mental health compared to before the pandemic, overall and stratified by gender, age group, number of chronic health conditions and household income tertile.

Results: Individuals who experienced pandemic-related appointment changes or had appointments not yet scheduled were less likely to have high self-rated mental health (aOR = 0.81 and 0.64, respectively) and more likely to have perceived worsening mental health (aOR = 1.50 and 1.94, respectively) than those with no scheduling problems. Adults who delayed contacting health care for pandemic-related reasons (e.g. fear of infection) or other reasons were less likely to have high self-rated mental health (aOR = 0.52 and 0.45, respectively) and more likely to have perceived worsening mental health (aOR = 2.31 and 2.43, respectively) than those who did not delay. Delaying contacting health care for pandemic-related reasons was associated with less favourable perceived mental health in all subgroups, while the association between perceived mental health and pandemic-related appointment changes was significant in some groups.

Conclusion: Health care barriers during the pandemic were associated with less favourable perceived mental health. These findings could inform health care resource allocation and public health messaging.

Keywords: *access to health care, access to health services, health care seeking behaviour, health care utilization, mental health, COVID-19 pandemic, adults, Canada*

Introduction

The COVID-19 pandemic brought about widespread changes to population mental health.¹⁻³ Mental health is an umbrella term that encompasses a variety of clinical and subjective (or perceived) indicators

and can include both positive mental health (defined as a state of well-being that allows us to “feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face”^{4,p.1}) and mental illness.⁵ Studies have found that the prevalence of positive mental

Highlights

- Adults in Canada who experienced health care appointment scheduling problems as a result of the COVID-19 pandemic or whose appointments were not yet scheduled had less favourable perceived mental health than people who had no scheduling problems.
- Similarly, adults in Canada who delayed seeking health care during the pandemic had less favourable perceived mental health than those who did not delay seeking health care.
- Experiencing pandemic-related appointment changes (vs. no appointment scheduling problems) was associated with less favourable perceived mental health for older adults, individuals with chronic health conditions, and individuals from low or middle-income households, even after adjustment.
- Delaying contacting health care for pandemic-related reasons (vs. not delaying contact) was associated with less favourable perceived mental health across sociodemographic groups.

health outcomes (e.g. high self-rated mental health) declined and the prevalence of negative mental health outcomes (e.g.

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recent suicidal ideation) increased during the pandemic compared to 2019 in Canada.¹⁻³ While numerous pandemic-related stressors may have influenced these trends, the aim of our study was to understand the link between health care barriers during the first year of the pandemic and perceived mental health.

Before the start of the pandemic, limitations in health care service availability—exemplified by long wait times and difficulties getting appointments—were among the most common health care accessibility challenges reported in Canada.⁶⁻⁸ Data from the 2013 Canadian Community Health Survey indicate that 29% of individuals aged 15 years and older who received health care in the past year reported difficulties accessing these services.⁷

The response to the pandemic further complicated existing resource constraints, and resource allocation strategies prioritized urgent treatments.⁹ Other public health precautions, such as physical distancing, increased disinfection between patient appointments and pre-appointment COVID-19 screenings,¹⁰ also reduced health care system capacity. Preliminary findings from the Survey on Access to Health Care and Pharmaceuticals during the Pandemic (SAHCPDP) indicate that 49% of the adults in the Canadian provinces who reported needing physical and/or mental health care during the first year of the pandemic experienced difficulties accessing it.¹¹ Specifically, 28% had at least one health care appointment cancelled, rescheduled, or delayed because of the pandemic, while 9% were unable to schedule at least one appointment.¹¹

Along with service availability issues, 30% delayed contacting a medical professional, with fear of exposure to COVID-19 and concerns about overloading the health care system given as just two of the common reasons for such delays.¹¹

Canada's Quality of Life framework identifies health care barriers as detrimental to well-being by listing multiple indicators related to timely access to health care and unmet needs.¹² In fact, findings from data collected in 1998/99 indicated that psychological distress in adults in Canada is associated with unmet health care needs due to barriers in health care availability, accessibility and acceptability.⁶ A study that used data from the 2002 Canadian

Community Health Survey – Mental Health and Well-Being reported that perceived barriers to accessing mental health services were associated with lower self-reported coping ability and psychological well-being among individuals aged 15 years and older who had recently experienced onset of a mental disorder.¹³

Surveys conducted during the pandemic in numerous countries suggest a link between difficulty accessing health care and experiencing negative mental health (e.g. symptoms of mental illness, such as anxiety and depression) among individuals with health conditions (i.e. individuals at high risk of severe illness from COVID-19 and persons with epilepsy).^{14,15} Moreover, data from June 2020 show that US adults who reported depression and anxiety symptoms had greater unmet health care needs due to the pandemic.¹⁶ However, a study of older adults in the Netherlands found that depression and anxiety symptoms were not significantly associated with appointment cancellations initiated by health care services.¹⁷

Studies have also explored the relationship between indicators of negative mental health and health care avoidance or delays in seeking health care during the pandemic. For instance, a study of US adults found that experiencing depression and anxiety symptoms was also associated with delaying medical care because of the pandemic.¹⁶ Furthermore, studies of older Dutch adults found that individuals who reported symptoms of depression or anxiety were more likely to delay contacting health care.^{17,18}

Taken together, these findings broadly suggest a link between health care barriers and negative mental health indicators during the pandemic,^{14,15,17,18} particularly among subpopulations with greater health care needs (e.g. at high risk of severe illness from COVID-19, older adults, persons with epilepsy).^{19,20} However, there remain several gaps in our understanding of the associations between health care barriers and mental health among Canadians during the pandemic. Some studies used aggregate measures of health care barriers,^{16,21} but examination of specific types of health care barriers could provide results that are more actionable for decision makers. In addition, the existing research focusses on indicators of negative mental health; examining positive mental health and

other perceived indicators of mental health (at the national level and among sociodemographic subpopulations) would offer a more complete understanding of Canadians' mental health during the pandemic. Finally, most studies examined health care barriers relatively early in the pandemic and over a relatively short time,^{14-16,18} and therefore may have captured a smaller number of problems with health care accessibility and missed potential associations with mental health over a longer period.

The present study attempts to fill these evidence gaps by using data from the SAHCPDP to characterize the perceived mental health (i.e. self-rated mental health, perceived worsening mental health compared to before the pandemic) of adults in Canada who experienced different health care barriers (i.e. appointment scheduling problems, delayed contacting health care) during the first year of the pandemic. Given differences in mental health, health care accessibility and health care needs across sociodemographic factors,^{6,7,19,20,22} we also examined subpopulations that may be particularly affected by health care barriers. This study examined (1) the association between appointment scheduling problems and perceived mental health; (2) the association between delaying contacting a medical professional and perceived mental health; and (3) whether any such associations were found among different sociodemographic groups, including genders, age groups, chronic health condition status and household income levels.

Methods

Data source

We used cross-sectional data from the SAHCPDP, collected from March to June 2021, with a target population of individuals aged 18 years and older residing in the Canadian provinces.²³ The survey excluded institutionalized individuals and people living on reserves and other Indigenous settlements. The SAHCPDP obtained a main sample and an Indigenous oversample. For each, a simple random sample of dwellings was selected within each province and then an adult was selected from each dwelling. The main sample used the Dwelling Universe File as the sampling frame, whereas the oversample used a list of individuals who self-identified as Indigenous in the 2016 Census. The

response rate was 46.2%, with a sample size of 25 268.²³ Of these respondents, 20 620 agreed to share their data with the Public Health Agency of Canada (PHAC). Respondents completed the survey using either an online questionnaire or computer-assisted telephone interviewing.

Because this study was based on aggregated, deidentified secondary data shared with PHAC under the purview of the federal *Statistics Act*, ethics approval was not required.

Eligibility criteria

We restricted analyses to those who reported needing one or more physical and/or mental health care services during the past 12 months ($n = 17\,335$). We removed proxy interviews to ensure that perceived mental health indicators were self-reported, resulting in a sample size of 17 199.

Measures

High self-rated mental health

Self-rated mental health was measured with the question “In general, how is your mental health?” Respondents could select one of the following: “Excellent,” “Very good,” “Good,” “Fair” or “Poor.” Those who selected “Excellent” or “Very good” were coded as having high self-rated mental health.^{24,25}

Perceived worsening mental health

Perceived worsening mental health was assessed with the question “Compared to before the COVID-19 pandemic, how would you say your mental health is now?” Respondents could select one of the following: “Much better now,” “Somewhat better now,” “About the same,” “Somewhat worse now” or “Much worse now.” Individuals who selected “Somewhat worse now” or “Much worse now” were coded as having perceived worsening mental health.^{26,27}

Appointment scheduling problems

Respondents were asked “Did you experience any of the following problems with the scheduling of your appointments?” Response options were “One or more of your appointments was cancelled, rescheduled or delayed due to the COVID-19 pandemic,” “One or more of your appointments was cancelled, rescheduled or delayed due to other reasons,” “One or more of your appointments has not been scheduled yet” and “Did not experience any problems

with the scheduling of your appointments.” Respondents could select more than one type of appointment scheduling problem.

In the overall analyses, we categorized respondents into one of four groups: (1) no appointment scheduling problems (reference group); (2) at least one pandemic-related appointment change (referred to as “pandemic-related appointment changes”); (3) at least one appointment change, but unrelated to the pandemic (referred to as “non-pandemic appointment changes”); and (4) at least one appointment that had not yet been scheduled, but no appointment changes (referred to as “appointments not yet scheduled”).

In the stratified analyses, we only examined individuals who experienced pandemic-related appointment changes and individuals who had no appointment scheduling problems. We excluded the remaining groups due to insufficient sample sizes.

Delays in contacting health care

Respondents were asked “In the past 12 months, did you delay contacting a medical professional about a problem with your physical, emotional or mental health for any of the following reasons?” Response options were “Fear of possible COVID-19 exposure in health care settings,” “Fear of possible COVID-19 exposure outside of health care settings,” “Concern of overloading the health care system,” “Other” and “Did not delay contacting a medical professional.” Respondents could select multiple reasons for delaying contact.

In the overall analyses, we categorized respondents into one of three groups: (1) did not delay contacting a medical professional (reference group); (2) delayed contacting a medical professional at least in part for pandemic-related reasons; and (3) delayed contacting a medical professional for other reasons only. In the stratified analyses, we did not include the group of respondents who delayed contacting a medical professional for other reasons only because of insufficient sample sizes.

Covariates

Several variables can confound the relationship between health care barriers and perceived mental health.^{3,6,7,11,19,20,22,28-32} We statistically controlled for gender (man, woman; the gender-diverse category was excluded due to insufficient

sample sizes), age (continuous), ethnicity (White, Indigenous, non-Indigenous racialized group member), immigrant status (born in Canada, born outside Canada), number of diagnosed chronic health conditions (0, 1, or 2+ of the 16, including “Other,” listed in the SAHCPDP questionnaire³³), household income tertile (low [$< \$60\,000$], middle [$\$60\,000$ – $\$110\,000$], high [$\geq \$110\,000$], derived from respondents’ estimates of their total household income before taxes in the previous year³³) and geographic location (British Columbia, the Prairie provinces [Alberta, Saskatchewan and Manitoba], Ontario, Quebec, Atlantic provinces [New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador]).

Analyses

All analyses were conducted using statistical package SAS Enterprise Guide version 7.1 (SAS Institute, Cary, NC, US). To account for the survey design and ensure the findings were representative of the target population, we used sampling weights. We estimated 95% confidence intervals, standard errors and coefficients of variation using bootstrap weights. Statistics Canada provided the sampling and bootstrap weights.

We calculated the overall prevalence of the different categories of appointment scheduling problems, delays in contacting health care, high self-rated mental health, perceived worsening mental health and the covariates. We also computed the prevalence of high self-rated mental health, perceived worsening mental health, categories of appointment scheduling problems and delays in contacting health care by gender, age group (young adults [18–34 years], middle-aged adults [35–64 years] and older adults [65+ years]), number of chronic health conditions and household income tertile. We also computed the prevalence of high self-rated mental health and perceived worsening mental health by each category of appointment scheduling problems and delays in contacting health care, overall and stratified by sociodemographic groups. We interpreted prevalence estimates with non-overlapping confidence intervals as significantly different.

We fitted unadjusted and adjusted logistic regression models to examine the associations between (1) appointment scheduling problems and high self-rated mental health; (2) appointment scheduling problems and perceived worsening mental

health; (3) delaying contacting health care and high self-rated mental health; and (4) delaying contacting health care and perceived worsening mental health. Each unadjusted model included only the main explanatory variable of interest, whereas adjusted models included the main explanatory variable and the covariates. To examine these associations in subpopulations, the unadjusted and adjusted logistic regression analyses were also stratified by gender, age group, number of chronic health conditions and household income tertile. We interpreted odds ratios with 95% confidence intervals that do not include 1.00 as statistically significant. When comparing odds ratios across stratified regression models, we interpreted odds ratios with non-overlapping confidence intervals as significantly different. The overall and stratified regression analyses (and their corresponding prevalence estimates) were restricted to complete case records for the relevant variables. Each pair of unadjusted and adjusted regression models were based on the same respondents.

Results

Descriptive statistics

Table 1 shows the distribution of sociodemographic characteristics in the study population.

The overall and stratified prevalence of the health care barriers and perceived mental health indicators are shown in Table 2. Overall, 42.9% (95% CI: 41.5–44.3) of adults who reported needing a health care service in the past 12 months had high self-rated mental health, with lower proportions of women (39.3%; 37.6–41.1) than of men (47.2%; 44.9–49.5) and adults with one (39.1%; 36.6–41.7) and multiple (34.6%; 32.2–37.0) chronic conditions than with no chronic conditions (49.4%; 47.1–51.8) reporting high self-rated mental health. The prevalence of high self-rated mental health was highest among older adults (52.2%; 50.0–54.5) and lowest among young adults (34.5%; 31.1–37.8).

Moreover, 37.7% (95% CI: 36.3–39.1) of adults who reported needing health care services also reported perceived worsening mental health, with higher proportions of women (41.3%; 39.5–43.1) than of men (33.5%; 31.4–35.6) and people in the high household income tertile (43.1%; 40.5–45.8)

TABLE 1
Sociodemographic characteristics of individuals who reported needing health care services during the past 12 months, March 2021–June 2021, Canada

Sociodemographic variable	% (95% CI)
Gender (n = 17 137)	
Man	46.6 (45.8–47.4)
Woman	53.4 (52.6–54.2)
Age group (n = 17 199)	
Young adults (18–34 years)	26.3 (25.4–27.1)
Middle-aged adults (35–64 years)	50.0 (49.2–50.8)
Older adults (65+ years)	23.7 (23.2–24.2)
Ethnicity (n = 17 040)	
White	72.9 (71.6–74.3)
Indigenous	3.3 (3.2–3.3)
Non-Indigenous racialized group member	23.8 (22.4–25.2)
Immigrant status (n = 17 187)	
Born in Canada	72.3 (71.0–73.6)
Born outside of Canada	27.7 (26.4–29.0)
Number of chronic health conditions (n = 16 786)	
0	47.3 (45.8–48.7)
1	29.4 (28.0–30.7)
≥2	23.4 (22.3–24.4)
Household income tertile (n = 15 553)	
Low (< \$60 000)	33.2 (31.8–34.6)
Middle (≥ \$60 000 and < \$110 000)	32.9 (31.6–34.3)
High (≥ \$110 000)	33.8 (32.4–35.2)
Geographic location (n = 17 199)	
Atlantic provinces ^a	6.8 (6.6–7.0)
British Columbia	14.2 (13.8–14.7)
Ontario	38.6 (37.8–39.4)
Prairie provinces ^b	18.0 (17.6–18.5)
Quebec	22.4 (21.8–22.9)

Source: Survey on Access to Health Care and Pharmaceuticals During the Pandemic (SAHCPDP).

Abbreviation: CI, confidence interval.

Notes: Missing values were removed when calculating the prevalence estimates.

^a Atlantic provinces include New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

^b Prairie provinces include Alberta, Saskatchewan and Manitoba.

than the low (36.2%; 33.7–38.7) and middle (36.2%; 33.6–38.7) household income tertiles reporting perceived worsening mental health. The prevalence of perceived worsening mental health was highest among young adults (53.8%; 50.4–57.2) and lowest among older adults (21.4%; 19.5–23.3). Further, 27.9% (26.6–29.2) experienced at least one pandemic-related appointment change, with higher proportions of women (29.7%; 28.0–31.4) than of men (25.9%; 23.9–27.8), and those with one (29.3%; 26.8–31.8) and multiple (34.3%; 31.8–36.9) chronic conditions versus no chronic conditions (23.8%; 21.9–25.7)

reporting one or more pandemic-related appointment changes.

Overall, 25.3% (95% CI: 24.0–26.5) of respondents delayed contacting health care for pandemic-related reasons. Higher proportions of women (28.1%; 26.5–29.8) than of men (21.8%; 19.8–23.7), young (30.3%; 27.0–33.6) and middle-aged (25.6%; 24.0–27.3) than of older adults (18.9%; 17.0–20.7) and adults with multiple chronic conditions (28.1%; 25.7–30.4) versus no chronic conditions (22.8%; 20.9–24.7) delayed contacting health care for pandemic-related reasons.

TABLE 2
Prevalence of perceived mental health indicators, appointment scheduling problems and delays in contacting health care, overall and stratified by gender, age group, number of chronic health conditions and household income tertile, Canada

	Prevalence, % (95% CI)											
	Overall	Gender		Age group, years			Number of chronic health conditions			Household income tertile		
	(n = 17 199)	Man (n = 7120)	Woman (n = 10017)	18–34 (n = 2719)	35–64 (n = 9087)	65+ (n = 5393)	None (n = 6368)	1 (n = 5006)	≥2 (n = 5412)	Low (n = 6073)	Middle (n = 5039)	High (n = 4441)
Perceived mental health												
High self-rated mental health	42.9 (41.5–44.3)	47.2 (44.9–49.5)	39.3 (37.6–41.1)	34.5 (31.1–37.8)	42.9 (41.0–44.9)	52.2 (50.0–54.5)	49.4 (47.1–51.8)	39.1 (36.6–41.7)	34.6 (32.2–37.0)	42.0 (39.5–44.5)	42.9 (40.3–45.6)	44.4 (41.7–47.1)
Perceived worsening mental health	37.7 (36.3–39.1)	33.5 (31.4–35.6)	41.3 (39.5–43.1)	53.8 (50.4–57.2)	37.0 (35.2–38.8)	21.4 (19.5–23.3)	37.9 (35.7–40.2)	38.5 (35.9–41.1)	36.2 (33.7–38.7)	36.2 (33.7–38.7)	36.2 (33.6–38.7)	43.1 (40.5–45.8)
Appointment scheduling problems												
No appointment scheduling problems	62.9 (61.6–64.3)	66.4 (64.3–68.4)	60.1 (58.2–61.9)	63.5 (60.2–66.9)	61.6 (59.8–63.4)	65.1 (62.9–67.3)	68.8 (66.8–70.8)	60.8 (58.2–63.5)	54.2 (51.7–56.8)	63.5 (61.1–65.9)	62.9 (60.2–65.6)	61.8 (59.2–64.5)
≥1 pandemic-related appointment change	27.9 (26.6–29.2)	25.9 (23.9–27.8)	29.7 (28.0–31.4)	28.3 (25.0–31.5)	28.8 (27.2–30.5)	25.6 (23.5–27.6)	23.8 (21.9–25.7)	29.3 (26.8–31.8)	34.3 (31.8–36.9)	25.8 (23.7–28.0)	28.7 (26.1–31.4)	30.1 (27.6–32.6)
≥1 appointment change but unrelated to the pandemic	3.5 (3.0–3.9)	3.0 (2.4–3.5)	3.8 (3.2–4.5)	3.4 (2.4–4.4)	3.2 (2.6–3.8)	4.0 (3.2–4.8)	2.6 (2.0–3.2)	3.9 (3.0–4.8)	4.8 (3.7–5.8)	4.2 (3.3–5.0)	3.2 (2.4–3.9)	3.0 (2.2–3.7)
≥1 appointment not yet scheduled but no appointment changes	5.7 (5.0–6.3)	4.8 (3.9–5.6)	6.4 (5.5–7.3)	4.8 (3.6–6.0)	6.3 (5.4–7.3)	5.3 (4.3–6.3)	4.8 (3.9–5.7)	6.0 (4.7–7.2)	6.7 (5.6–7.7)	6.5 (5.3–7.7)	5.2 (4.2–6.3)	5.1 (4.0–6.3)
Delays in contacting health care												
Did not delay contact	70.4 (69.0–71.7)	73.9 (71.8–76.1)	67.5 (65.8–69.2)	63.4 (60.0–66.8)	70.2 (68.4–71.9)	78.6 (76.8–80.5)	73.0 (71.0–75.1)	68.8 (66.1–71.4)	67.6 (65.1–70.1)	68.5 (66.0–70.9)	69.7 (67.1–72.3)	71.8 (69.4–74.1)
Delayed contact for pandemic-related reasons	25.3 (24.0–26.5)	21.8 (19.8–23.7)	28.1 (26.5–29.8)	30.3 (27.0–33.6)	25.6 (24.0–27.3)	18.9 (17.0–20.7)	22.8 (20.9–24.7)	26.5 (24.1–28.9)	28.1 (25.7–30.4)	25.9 (23.7–28.1)	25.9 (23.4–28.3)	25.0 (22.7–27.3)
Delayed contact only for other reasons	4.4 (3.7–5.1)	4.3 (3.1–5.5)	4.4 (3.6–5.2)	6.3 (4.4–8.3) ^c	4.2 (3.4–5.0)	2.5 (1.8–3.2)	4.1 (3.2–5.1)	4.7 (3.1–6.4) ^c	4.3 (3.3–5.4)	5.6 (4.2–7.0)	4.4 (3.1–5.7)	3.2 (2.3–4.2) ^c

Source: Survey on Access to Health Care and Pharmaceuticals During the Pandemic (SAHCPDP).

Abbreviation: CI, confidence interval.

Notes: Missing values were removed when calculating prevalence.

^c Results should be interpreted with caution due to high sampling variability (coefficients of variation between 15 and 35).

Appointment scheduling problems and perceived mental health

The regression results for appointment scheduling problems are presented in Table 3.

Overall, compared to those who experienced no appointment scheduling problems, those who faced pandemic-related appointment changes (OR = 0.72, 95% CI: 0.62–0.83; aOR = 0.81, 95% CI: 0.70–0.95) and those with appointments not yet scheduled (OR = 0.61, 0.47–0.80; aOR = 0.64, 0.49–0.84) had lower odds of reporting high self-rated mental health before and after adjusting for covariates. The odds of high self-rated mental health did not differ significantly between those who experienced non-pandemic appointment changes and those who experienced no appointment scheduling problems (Table 3).

Stratified analyses indicated that, compared to those who experienced no appointment scheduling problems, the unadjusted odds of reporting high self-rated mental health were significantly lower for those who experienced pandemic-related appointment changes among men (OR = 0.76, 95% CI: 0.60–0.96), women (OR = 0.70, 0.58–0.83) and younger adults (OR = 0.65, 0.44–0.96) (Table 3).

Both the unadjusted and adjusted odds of reporting high self-rated mental health were significantly lower for those who experienced pandemic-related appointment changes among older adults (OR = 0.57, 95% CI: 0.45–0.73; aOR = 0.60, 95% CI: 0.47–0.77), those with 1 chronic condition (OR = 0.63, 0.49–0.82; aOR = 0.73, 0.56–0.95) and 2+ chronic conditions (OR = 0.63, 0.48–0.82; aOR = 0.74, 0.57–0.97), and those in low-income households (OR = 0.63, 0.49–0.80; aOR = 0.72, 0.56–0.91) and middle-income households (OR = 0.62, 0.48–0.80; aOR = 0.72, 0.55–0.93). The odds of high self-rated mental health did not differ between the two appointment scheduling groups for middle-aged adults, those with no chronic conditions and those in high-income households (Table 3).

Overall, compared to those who had no appointment scheduling problems, respondents who experienced pandemic-related appointment changes (aOR = 1.50, 95% CI: 1.28–1.75) and those with appointments that were not yet scheduled (aOR = 1.94, 1.50–2.52) had greater odds of reporting

perceived worsening mental health, before and after adjusting for covariates. However, the odds of perceived worsening mental health did not significantly differ between those who faced non-pandemic appointment changes and those who did not experience any appointment scheduling problems (Table 3).

The unadjusted and adjusted odds of reporting perceived worsening mental health were significantly greater among those who faced pandemic-related appointment changes compared to those who faced no appointment scheduling problems among men (OR = 1.36, 95% CI: 1.06–1.75; aOR = 1.34, 95% CI: 1.04–1.73), women (OR = 1.80, 1.50–2.17; aOR = 1.65, 1.35–2.01), those with no chronic conditions (OR = 1.46, 1.16–1.83; aOR = 1.44, 1.14–1.82), 1 chronic condition (OR = 1.99, 1.54–2.59; aOR = 1.78, 1.35–2.34), and 2+ chronic conditions (OR = 1.60, 1.21–2.11; aOR = 1.38, 1.05–1.81), those in low-income households (OR = 1.64, 1.28–2.10; aOR = 1.57, 1.22–2.02) and middle-income households (OR = 1.95, 1.49–2.55; aOR = 1.79, 1.35–2.39), and middle-aged (OR = 1.54, 1.28–1.85; aOR = 1.44, 1.20–1.74) and older adults (OR = 2.23, 1.70–2.91; aOR = 2.25, 1.71–2.96). The unadjusted odds of reporting perceived worsening mental health were also significantly higher for young adults (OR = 1.47, 1.03–2.10) and those in high-income households (OR = 1.32, 1.02–1.71) who experienced pandemic-related appointment changes (Table 3).

Delays in contacting health care and perceived mental health

The regression results for delays in contacting health care are presented in Table 4.

Overall, compared to those who did not delay contacting health care, those who delayed contacting health care for pandemic-related reasons (OR = 0.46, 95% CI: 0.39–0.54; aOR = 0.52, 95% CI: 0.44–0.62) and those who delayed only for other reasons (OR = 0.38, 0.26–0.55; aOR = 0.45, 0.31–0.66) were less likely to report high self-rated mental health, before and after adjustment (Table 4).

The unadjusted and adjusted odds of high self-rated mental health were significantly lower among those who delayed contacting health care for pandemic-related reasons compared to those who did not delay contacting health care (OR range from

0.38–0.55; aOR range from 0.41–0.60) across gender, age group, household income tertile and chronic health condition categories (Table 4).

Overall, compared to those who did not delay contacting health care, the odds of reporting perceived worsening mental health were significantly greater among those who delayed contacting health care for pandemic-related reasons (OR = 2.51, 95% CI: 2.15–2.93; aOR = 2.31, 95% CI: 1.97–2.72) and for other reasons (OR = 2.97, 2.09–4.21; aOR = 2.43, 1.68–3.52), before and after adjustment. The unadjusted and adjusted odds of perceived worsening mental health were significantly greater among those who delayed contacting health care for pandemic-related reasons compared to those who did not delay contacting health care (OR range from 2.09–3.73; aOR range from 2.02–3.67) across gender, age group, household income tertile and chronic health condition categories. Notably, the association between delaying contact due to pandemic-related reasons and perceived worsening mental health was stronger among older adults (OR = 3.73, 2.82–4.95; aOR = 3.67, 2.76–4.88) than among middle-aged adults (OR = 2.16, 1.78–2.62; aOR = 2.16, 1.78–2.62) (Table 4).

Discussion

The COVID-19 pandemic led to reduced health care provision for non-COVID-19 health issues,⁹ and decreased willingness among some to seek health care because of concerns about contracting COVID-19 or overloading the health care system.¹¹ These widespread changes in health care availability and health care-seeking behaviours during the pandemic coincided with declines in population mental health.^{1,3} Our study examined whether experiencing health care barriers might be one explanation for declines in perceived mental health. We found that several health care barriers were associated with less favourable perceived mental health indicators; these included pandemic-related appointment changes, having appointments not yet scheduled, and delaying contact with health care for pandemic-related or other reasons.

Beyond preventing mortality and disease, timely access to health care is a key resource for achieving mental and physical well-being.¹² The vast majority of those who experienced difficulties accessing health

TABLE 3
Unadjusted and adjusted associations between appointment scheduling problems
and perceived mental health indicators, overall and stratified, Canada

	High self-rated mental health			Perceived worsening mental health		
	% (95% CI)	OR (95% CI)	aOR (95% CI)	% (95% CI)	OR (95% CI)	aOR (95% CI)
Overall		n = 14813		n = 14802		
No appointment scheduling problems	46.5 (44.5–48.5)	Ref.	Ref.	34.3 (32.4–36.1)	Ref.	Ref.
≥1 pandemic-related appointment change	38.3 (35.3–41.3)	0.72 (0.62–0.83)	0.81 (0.70–0.95)	45.7 (42.7–48.7)	1.62 (1.39–1.87)	1.50 (1.28–1.75)
≥1 appointment change but unrelated to the pandemic	41.0 (34.2–47.8)	0.80 (0.59–1.08)	0.94 (0.70–1.26)	39.6 (33.0–46.2)	1.26 (0.94–1.68)	1.20 (0.89–1.62)
≥1 appointment not yet scheduled but no appointment changes	34.7 (29.1–40.2)	0.61 (0.47–0.80)	0.64 (0.49–0.84)	49.6 (43.5–55.6)	1.89 (1.46–2.43)	1.94 (1.50–2.52)
Gender						
Man		n = 5636		n = 5631		
No appointment scheduling problems	49.9 (46.9–52.9)	Ref.	Ref.	31.9 (29.1–34.6)	Ref.	Ref.
≥1 pandemic-related appointment change	43.1 (38.2–47.9)	0.76 (0.60–0.96)	0.80 (0.63–1.01)	38.9 (33.9–44.0)	1.36 (1.06–1.75)	1.34 (1.04–1.73)
Woman		n = 7642		n = 7638		
No appointment scheduling problems	43.1 (40.5–45.6)	Ref.	Ref.	36.7 (34.2–39.2)	Ref.	Ref.
≥1 pandemic-related appointment change	34.5 (31.2–37.8)	0.70 (0.58–0.83)	0.84 (0.70–1.003)	51.1 (47.4–54.8)	1.80 (1.50–2.17)	1.65 (1.35–2.01)
Age group						
18–34 years		n = 2053		n = 2050		
No appointment scheduling problems	39.0 (34.0–43.9)	Ref.	Ref.	51.0 (46.2–55.8)	Ref.	Ref.
≥1 pandemic-related appointment change	29.3 (22.4–36.1)	0.65 (0.44–0.96)	0.77 (0.52–1.14)	60.4 (53.3–67.6)	1.47 (1.03–2.10)	1.31 (0.91–1.90)
35–64 years		n = 7173		n = 7166		
No appointment scheduling problems	45.4 (42.7–48.1)	Ref.	Ref.	33.6 (31.2–36.0)	Ref.	Ref.
≥1 pandemic-related appointment change	40.9 (37.0–44.9)	0.83 (0.68–1.02)	0.96 (0.78–1.17)	43.8 (40.1–47.5)	1.54 (1.28–1.85)	1.44 (1.20–1.74)
65+ years		n = 4052		n = 4053		
No appointment scheduling problems	57.1 (54.0–60.1)	Ref.	Ref.	17.2 (15.0–19.4)	Ref.	Ref.
≥1 pandemic-related appointment change	43.3 (38.5–48.1)	0.57 (0.45–0.73)	0.60 (0.47–0.77)	31.6 (26.9–36.3)	2.23 (1.70–2.91)	2.25 (1.71–2.96)
Number of chronic health conditions						
None		n = 5284		n = 5280		
No appointment scheduling problems	51.0 (48.0–54.1)	Ref.	Ref.	35.6 (32.7–38.5)	Ref.	Ref.
≥1 pandemic-related appointment change	49.1 (44.1–54.1)	0.93 (0.73–1.17)	0.94 (0.73–1.19)	44.6 (39.7–49.5)	1.46 (1.16–1.83)	1.44 (1.14–1.82)
1		n = 3962		n = 3957		
No appointment scheduling problems	43.0 (39.5–46.5)	Ref.	Ref.	33.7 (30.3–37.2)	Ref.	Ref.
≥1 pandemic-related appointment change	32.3 (27.6–37.0)	0.63 (0.49–0.82)	0.73 (0.56–0.95)	50.4 (45.2–55.5)	1.99 (1.54–2.59)	1.78 (1.35–2.34)

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TABLE 3 (continued)
Unadjusted and adjusted associations between appointment scheduling problems and perceived mental health indicators, overall and stratified, Canada

	High self-rated mental health			Perceived worsening mental health		
	% (95% CI)	OR (95% CI)	aOR (95% CI)	% (95% CI)	OR (95% CI)	aOR (95% CI)
2+		n = 4032			n = 4032	
No appointment scheduling problems	39.3 (35.8–42.8)	Ref.	Ref.	31.5 (28.0–34.9)	Ref.	Ref.
≥1 pandemic-related appointment change	28.9 (24.3–33.5)	0.63 (0.48–0.82)	0.74 (0.57–0.97)	42.3 (37.0–47.6)	1.60 (1.21–2.11)	1.38 (1.05–1.81)
Household income tertile						
Low		n = 5122			n = 5116	
No appointment scheduling problems	45.7 (42.3–49.0)	Ref.	Ref.	32.2 (28.8–35.6)	Ref.	Ref.
≥1 pandemic-related appointment change	34.5 (29.8–39.1)	0.63 (0.49–0.80)	0.72 (0.56–0.91)	43.8 (39.2–48.5)	1.64 (1.28–2.10)	1.57 (1.22–2.02)
Middle		n = 4323			n = 4326	
No appointment scheduling problems	47.4 (44.0–50.7)	Ref.	Ref.	30.5 (27.3–33.7)	Ref.	Ref.
≥1 pandemic-related appointment change	35.7 (30.5–40.8)	0.62 (0.48–0.80)	0.72 (0.55–0.93)	46.1 (40.5–51.6)	1.95 (1.49–2.55)	1.79 (1.35–2.39)
High		n = 3833			n = 3827	
No appointment scheduling problems	46.4 (42.8–50.0)	Ref.	Ref.	40.1 (36.7–43.6)	Ref.	Ref.
≥1 pandemic-related appointment change	44.0 (38.7–49.4)	0.91 (0.70–1.18)	1.01 (0.77–1.32)	47.0 (41.7–52.2)	1.32 (1.02–1.71)	1.25 (0.96–1.63)

Source: Survey on Access to Health Care and Pharmaceuticals During the Pandemic (SAHCPDP).

Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; OR, odds ratio; Ref., reference group.

Notes: Adjusted models included gender, age, racialized group membership, immigrant status, number of chronic health conditions (0, 1, 2+), household income tertile, and geographic location as covariates. Bolded unadjusted and adjusted odds ratio estimates have confidence intervals that exclude the null odds ratio of 1.00 and are considered statistically significant.

care during the pandemic reported that this had a negative impact on their life, with worry, stress or anxiety; pain; worsening health and problems with daily living activities being commonly reported impacts.¹¹ Experiencing appointment scheduling problems could negatively affect perceived mental health directly and/or indirectly by influencing other determinants of mental health (e.g. health status, physical activity, coping ability, sense of control and self-efficacy).²⁵ Future research could explore how prolonged health care wait times might be associated with additional indicators of mental health (and their determinants), including positive mental health outcomes beyond high self-rated mental health and/or validated measures of mental illness.

Recognizing that the impacts of health care barriers can vary across subgroups, we stratified our analyses by gender, age group, number of chronic health conditions and household income tertile. We found that the relationship between

pandemic-related appointment changes and both indicators of perceived mental health persisted for older adults, individuals with one or multiple chronic health conditions, and those in low- and middle-income households. Since these subpopulations tend to have greater health care needs,^{19,34} pandemic-related appointment changes might have had a disproportionate impact on their perceived mental health.¹² These findings can inform decision makers about health care resource allocation by focusing on the potential mental health consequences of prolonged wait times, especially for those with the greatest needs.

Deciding to postpone addressing one's current health care needs to avoid risking COVID-19 exposure or overloading the health care system may cause individuals to worry and feel stressed. Our results show that adults in Canada who delayed contacting health care for pandemic-related or other reasons were less likely to report high self-rated mental health and more likely to report perceived worsening

mental health than those who did not delay contacting health care. Moreover, across all sociodemographic groups, those who delayed contacting health care for pandemic-related reasons had less favourable perceived mental health compared to those who did not delay.

These findings add to the existing literature showing that greater COVID-19 risk perception is associated with worse mental health, including a lower likelihood of reporting high self-rated mental health,³⁵ and increased depression and anxiety symptoms.³⁶ The uncertainty and stress of having unmet health care needs and deteriorating health resulting from delaying health care may compound these effects. Indeed, recent research found that older US adults with low self-rated mental health or low self-rated physical health were more likely to perceive negative health effects due to delayed health care.²¹ Delaying contacting health care could also reflect an avoidance coping style, which has been associated with higher levels of

TABLE 4
Unadjusted and adjusted associations between delaying contacting health care
and perceived mental health indicators, overall and stratified, Canada

	High self-rated mental health			Perceived worsening mental health		
	% (95% CI)	OR (95% CI)	aOR (95% CI)	% (95% CI)	OR (95% CI)	aOR (95% CI)
Overall		n = 14 826		n = 14 814		
Did not delay contact	48.9 (47.1–50.8)	Ref.	Ref.	31.7 (30.0–33.5)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	30.4 (27.5–33.4)	0.46 (0.39–0.54)	0.52 (0.44–0.62)	53.9 (50.6–57.1)	2.51 (2.15–2.93)	2.31 (1.97–2.72)
Delayed contact only due to other reasons	26.6 (19.6–33.7)	0.38 (0.26–0.55)	0.45 (0.31–0.66)	58.0 (49.7–66.2)	2.97 (2.09–4.21)	2.43 (1.68–3.52)
Gender						
Man		n = 6012		n = 6007		
Did not delay contact	52.1 (49.4–54.9)	Ref.	Ref.	29.1 (26.5–31.7)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	36.1 (30.9–41.2)	0.52 (0.40–0.66)	0.56 (0.44–0.73)	46.2 (41.0–51.4)	2.09 (1.63–2.68)	2.02 (1.55–2.62)
Woman		n = 8212		n = 8204		
Did not delay contact	45.7 (43.3–48.1)	Ref.	Ref.	34.4 (32.0–36.8)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	26.5 (23.2–29.8)	0.43 (0.35–0.52)	0.49 (0.40–0.61)	59.2 (55.5–62.9)	2.77 (2.29–3.34)	2.56 (2.09–3.13)
Age group						
18–34 years		n = 2155		n = 2151		
Did not delay contact	40.6 (35.6–45.7)	Ref.	Ref.	48.2 (43.4–52.9)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	27.3 (21.3–33.3)	0.55 (0.38–0.79)	0.60 (0.41–0.88)	66.3 (59.7–72.8)	2.11 (1.49–3.00)	2.05 (1.41–2.97)
35–64 years		n = 7663		n = 7656		
Did not delay contact	48.2 (45.7–50.7)	Ref.	Ref.	31.9 (29.6–34.2)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	30.9 (27.2–34.6)	0.48 (0.39–0.59)	0.54 (0.44–0.67)	50.3 (46.2–54.3)	2.16 (1.78–2.62)	2.16 (1.78–2.62)
65+ years		n = 4406		n = 4404		
Did not delay contact	58.0 (55.4–60.7)	Ref.	Ref.	16.4 (14.5–18.3)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	34.7 (29.2–40.2)	0.38 (0.29–0.50)	0.41 (0.31–0.54)	42.3 (36.3–48.3)	3.73 (2.82–4.95)	3.67 (2.76–4.88)
Chronic health conditions						
None		n = 5535		n = 5529		
Did not delay contact	54.5 (51.7–57.3)	Ref.	Ref.	32.7 (30.0–35.4)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	38.3 (33.4–43.2)	0.52 (0.41–0.65)	0.55 (0.43–0.70)	53.2 (48.1–58.4)	2.35 (1.84–2.99)	2.20 (1.70–2.84)
1		n = 4233		n = 4229		
Did not delay contact	45.2 (42.0–48.4)	Ref.	Ref.	32.3 (29.2–35.5)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	26.3 (21.5–31.1)	0.43 (0.33–0.57)	0.54 (0.40–0.73)	55.2 (49.8–60.6)	2.58 (1.97–3.38)	2.26 (1.69–3.02)

Continued on the following page

TABLE 4 (continued)
Unadjusted and adjusted associations between delaying contacting health care and perceived mental health indicators, overall and stratified, Canada

	High self-rated mental health			Perceived worsening mental health		
	% (95% CI)	OR (95% CI)	aOR (95% CI)	% (95% CI)	OR (95% CI)	aOR (95% CI)
2+		n = 4456		n = 4453		
Did not delay contact	41.1 (37.9–44.4)	Ref.	Ref.	28.9 (25.9–31.9)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	21.8 (17.4–26.2)	0.40 (0.30–0.54)	0.47 (0.35–0.63)	53.2 (47.9–58.6)	2.80 (2.17–3.63)	2.53 (1.92–3.33)
Household income tertile						
Low		n = 5526		n = 5517		
Did not delay contact	48.3 (45.2–51.4)	Ref.	Ref.	29.4 (26.5–32.2)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	29.0 (23.9–34.0)	0.44 (0.33–0.58)	0.49 (0.37–0.65)	51.8 (46.6–57.1)	2.59 (2.02–3.32)	2.25 (1.73–2.92)
Middle		n = 4616		n = 4617		
Did not delay contact	48.8 (45.6–52.0)	Ref.	Ref.	28.3 (25.5–31.1)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	29.5 (24.2–34.8)	0.44 (0.33–0.58)	0.52 (0.39–0.70)	53.0 (47.3–58.7)	2.86 (2.20–3.72)	2.68 (2.01–3.57)
High		n = 4082		n = 4077		
Did not delay contact	49.6 (46.3–53.0)	Ref.	Ref.	37.3 (34.0–40.5)	Ref.	Ref.
Delayed contact due to pandemic-related reasons	32.9 (28.2–37.5)	0.50 (0.39–0.64)	0.55 (0.42–0.71)	56.8 (51.8–61.9)	2.22 (1.73–2.85)	2.19 (1.69–2.85)

Source: Survey on Access to Health Care and Pharmaceuticals During the Pandemic (SAHCPDP).

Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; OR, odds ratio; Ref., reference group.

Notes: Adjusted models included gender, age, racialized group membership, immigrant status, number of chronic health conditions (0, 1, 2+), household income tertile and geographical location as covariates. Bolded unadjusted and adjusted odds ratio estimates have confidence intervals that exclude the null odds ratio of 1.00, and are considered statistically significant.

depression and anxiety symptoms during the pandemic.³⁷

The robust association between delaying contacting health care and less favourable perceived mental health in our study highlights the importance of continued public health messaging encouraging people to seek health care that they need. Primary care providers and other clinicians may play an important role in counselling patients who are hesitant to seek care and in addressing COVID-19 safety concerns. Access to alternative care modalities, like telehealth,³⁸ as well as implementing health and safety measures, such as COVID-19 symptom screening, and informing potential patients of these might reduce the prevalence of delays in contacting health care. Additional research could explore other reasons for delaying health care during the pandemic and identify points for intervention. Future Canadian research might also consider other subpopulations experiencing barriers to seeking health care during the pandemic, such as those

identified in a US study (unpaid caregivers for adults, people with disabilities and racialized group members).³⁹

Strengths and limitations

Our study provides a nuanced examination of the relationship between various types of health care barriers and different indicators of perceived mental health among adults in Canada during the pandemic. The large, population-based sample allowed us to examine these associations across different sociodemographic groups and control for important covariates.

This study is not without limitations. The SAHCPDP used a cross-sectional design, which precludes inferring the directionality and causality of findings. The response rate for the SAHCPDP was under 50%, but survey weights were developed to mitigate biases associated with nonresponse. Children and youth, institutionalized populations and people living in the territories, on reserves or in other Indigenous

settlements were not included in the survey, which affects the generalizability of the findings; these population groups may also be vulnerable to the effects of health care barriers.⁴⁰⁻⁴²

The survey was self-reported, and therefore susceptible to misclassification of household income and recall bias with respect to health care experiences and needs. The reported household income may not reflect respondents' typical, pre-pandemic income if they experienced employment loss or were able to make use of the COVID-19 relief programs available during 2020.⁴³ In addition, some stratified analyses had covariates with high sampling variability.

We were only able to examine one positive mental health indicator, which limits a broader understanding of the relationship between health care barriers and positive mental health (and overall mental health). Our study aggregated health care barriers across all health care services, but the

mental health implications of health care barriers may differ depending on the type of service (e.g. urgent vs. routine, physical vs. mental). It is also unclear how many appointment changes were initiated by the health care provider or the patient. The way the appointment was changed—whether it was cancelled, rescheduled or delayed—is also unknown. We aggregated the experiences of individuals who delayed contacting health care due to concerns about COVID-19 infection and due to concerns about burdening the health care system. These varied pandemic-related motivations could have differing implications for different facets of mental health. Finally, we applied a highly conservative approach to testing differences among prevalences and ORs by using non-overlapping CIs to highlight statistically significant differences of interest.

Conclusion

During the first year of the COVID-19 pandemic, several health care barriers, including pandemic-related appointment changes, appointments not yet scheduled and delaying contacting health care for any reason were negatively associated with high self-rated mental health and positively associated with perceived worsening mental health. The association between pandemic-related appointment changes and unfavourable perceived mental health persisted across sociodemographic groups that tend to have greater health care needs. On the other hand, the relationship between delaying contacting health care for pandemic-related reasons and unfavourable perceived mental health persisted for all examined sociodemographic groups. As we navigate the recovery period of the pandemic, continued surveillance is necessary to track the prevalence of health care barriers and mental health in the Canadian population.

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Conflict of interest

The authors have no conflicts of interest.

Authors' contributions and statement

MS – Methodology, formal analysis, writing – original draft, writing – review & editing.

CC – Conceptualization, methodology, validation, writing – review & editing, supervision.

LO – Methodology, validation, writing – review & editing, supervision.

KCR – Methodology, writing – review & editing, supervision.

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Release notice

Canadian Cancer Statistics 2023

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Just released!

[Canadian Cancer Statistics 2023](#) was released on 8 November 2023.



The publication of the *Canadian Cancer Statistics 2023* was produced through a collaboration between the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada, with data provided by the provincial and territorial cancer registries and analyses completed by Statistics Canada and the Public Health Agency of Canada. *Canadian Cancer Statistics 2023* provides estimates of cancer incidence, mortality and survival for 2023.

Highlights

- For both males and females, lung cancer mortality has decreased by 3.8% per year since 2015. This represents the largest annual decline in mortality rates across all cancer types reported, and the fastest decline in lung cancer mortality reported to date in Canada.
- Probability of developing cancer over a lifetime is 45% and similar for males and females.
- For males, the largest decreases in cancer incidence were for: colorectal (-4.0% per year since 2014), lung (-2.6% per year since 2012) and leukemia (-2.0% per year since 2011).
- For females, the largest decreases in cancer incidence were for: colorectal (-3.1% per year since 2014), thyroid (-2.6% per year since 2012) and ovarian (-2.6% per year since 2014).
- The largest significant increase in cancer incidence among males was for melanoma (2.2% per year since 1984).
- Among females, cervical cancer is now the most rapidly increasing cancer (3.7% per year since 2015), marking the first significant increase in cervical cancer incidence since 1984.
- Approximately 1 in 4 Canadians are expected to die from cancer.
- The probability of dying from cancer is slightly higher for males (24%) than for females (21%).
- For males, the largest decreases in cancer mortality after lung (-4.3% per year since 2014) were for: bladder (-3.4% per year since 2016), kidney and renal pelvis (-3.1% per year since 2014) and melanoma (-2.6% per year since 2013).
- For females, the largest decreases in mortality after lung (-4.1% per year since 2016) were for: Hodgkin lymphoma (-3.2% per year since 1984), colorectal (-3.1% per year since 2014) and melanoma (-3.0% per year since 2014).

Access or download the latest [Canadian Cancer Statistics and related resources](#).



This publication was developed by the Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada with cancer data provided by the provincial and territorial cancer registries through the Canadian Cancer Registry. [cancer.ca/statistics](#)

Call for papers: Generating stronger evidence to inform policy and practice: natural experiments on built environments, health behaviours and chronic diseases

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Guest editors: Dr. Stephanie Prince Ware (Public Health Agency of Canada), Dr. Gavin McCormack (University of Calgary)

HPCDP Journal Editors: Robert Geneau and Margaret de Groh (Public Health Agency of Canada)

Where we work, learn, play, eat and live has important implications for health. The built environment has been associated with the development of chronic disease, and with health behaviours often seen as critical pathways for this relationship.^{1,2} Built environments refer to components of the physical environment that are human-made or human-modified and include structures and buildings, recreation facilities, green spaces and parks, transportation systems and community design.

Natural experiments are interventions that occur without a researcher's ability to manipulate the intervention or exposure to the intervention.^{3,4} Natural experiments offer the opportunity to evaluate the effects of "naturally occurring" interventions such as changes to the built environment (e.g. creation of a new bike path, park improvements, infrastructure changes to schools or workplaces, construction of a new recreation facility or grocery store) on health behaviours and chronic disease risk. Natural experiments are often more practical for investigating the health impacts of environmental interventions when compared to traditional experimental studies (e.g. randomized controlled trials). Compared to cross-sectional studies, natural experiments provide a means to generate rigorous evidence to better establish causality, as well as to understand the implementation of interventions in "real-world" scenarios.

This special issue answers the 2017 Canadian Public Health Officer annual report's call to further evaluate the health impacts of community design features in Canada.⁵ This special issue resonates with the expanding scholarly and policy-oriented interest in the utility of natural experiments as a critical tool in advancing the body of evidence and for informing interventions to improve public and population health.^{6,7} Specifically, the objective of this special issue on natural experiments is to provide timely evidence to further understand the effectiveness of built environment interventions on health behaviours and chronic disease prevention in a Canadian context.

Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice is seeking relevant topical research articles that present new findings or synthesize/review existing evidence on natural experiments of the built environment (or related policies) that influence health behaviours with implications for chronic disease prevention in Canada.

Relevant topic areas include, but are not limited to:

- Built environments, including community or neighbourhoods, workplaces, schools, transportation infrastructure, home environments, recreation environments, parks, playgrounds, green spaces, public open spaces, natural environments and seniors' residences.
- All health-related behaviours, including physical activity, sedentary behaviour, sleep, food consumption, smoking and substance use.
- Chronic diseases and health-related outcomes, including body mass index, fitness, blood pressure, blood lipids, blood sugar, injuries, falls, mental health, stress, depression, anxiety, Alzheimer's disease, dementia, obesity, metabolic syndrome, cardiovascular disease, cancer, diabetes and lung disease.

International submissions will be considered if they include Canadian data, results (e.g. as part of multi-country studies or global comparisons) and/or evidence-based discussion of implications for community or population health in Canada.

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