

Health care utilization differences between First Nations people and the general population with inflammatory bowel disease: a retrospective cohort study from Saskatchewan, Canada

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Abstract

Background: Indigenous people in Canada often face barriers to access specialized care, with limited data in evaluating health care utilization among Indigenous people with inflammatory bowel disease (IBD). We aimed to compare health care utilization between First Nations patients and those in the general population diagnosed with IBD in Saskatchewan.

Methods: We conducted a patient-oriented, population-based, retrospective cohort study by linking administrative health databases of Saskatchewan between fiscal years 1998/99 and 2017/18. We designed and completed this study in partnership with Indigenous patients and family advocates. We applied a validated algorithm to identify IBD incident cases and then used the self-declared First Nations status variable to divide those cases. We applied a 1:5 ratio for age and sex matching and used Cox proportional models to assess associations. Hazard ratios (HRs) and 95% confidence intervals (CIs) were reported.

Results: We created a matched cohort with 696 IBD incident cases: 116 First Nations patients and 580 patients in the general population. We observed differences between the groups for IBD-specific hospital admissions (HR 1.33, 95% CI 1.01–1.75), IBD-related hospital admissions (HR 1.55, 95% CI 1.20–2.01), medication claims for IBD (HR 0.52, 95% CI 0.41–0.65) and 5-aminosalicylic acid claims (HR 0.56, 95% CI 0.45–0.71) adjusting by rural or urban residence and diagnosis type. There were no significant differences in the hazard rate of outpatient gastroenterology visits (HR 1.13, 95% CI 0.90–1.41), colonoscopies (HR 1.14, 95% CI 0.92–1.41) and surgeries for IBD (HR 1.14, 95% CI 0.80–1.64).

Interpretation: We identified that First Nations patients diagnosed with IBD had a higher rate of hospital admissions owing to IBD than patients in the general population diagnosed with IBD. We also found an inverse association between First Nations status and having prescription medication claims for IBD.

Oppression and racism are ongoing problems faced by Indigenous people,¹ a population that continues to have inequitable health outcomes compared with the Canadian general population.² Indigenous people often access health care when they are experiencing more severe or complex health care challenges.³ Health care disparities among the Indigenous community is a problem previously studied;^{4–7} however, little is known about access to care for inflammatory bowel disease (IBD) among Indigenous people. Inflammatory bowel disease, including Crohn disease and ulcerative colitis, is a chronic, idiopathic and incurable disorder, causing inflammation of the gastrointestinal tract.⁸ Canada has one of the highest prevalence and incidence rates of IBD in the world.^{9,10} In 2018, 0.7% of Canadians lived with IBD.¹¹ By 2030, researchers estimate that 1% of the Canadian population will have IBD.¹¹ Our research group (IBD Among Indigenous Peoples Research Team)

reported that the prevalence of IBD among First Nations patients, the largest Indigenous subgroup in Canada, doubled between 1999 and 2016 (from 64 per 100 000 to 142 per 100 000 population) in Saskatchewan and estimated an annual average increase of 4.2%.¹² We also observed IBD annual incidence rates among First Nations patients, at around 11 per 100 000 inhabitants, and identified a pre-dominance of ulcerative colitis relative to Crohn disease among First Nations patients.¹²

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Indigenous patient and family advocates (Indigenous people or family members of an Indigenous person living with IBD) have manifested concerns about the access to IBD care,¹³ as data are lacking comparing IBD health care utilization between First Nations patients and the general population. Furthermore, one-half of First Nations patients live on-reserve in Saskatchewan.¹⁴ People with IBD in rural areas may not receive gastroenterologist care as often as those living with IBD in urban centres.¹⁵ This issue may also affect the health of First Nations patients living with IBD.^{15,16} We aimed to compare health care utilization (i.e., outpatient gastroenterologist visits, colonoscopies, IBD medication claims, IBD-specific and -related hospital admissions and surgeries for IBD) between First Nations patients and those from the general population living with IBD in Saskatchewan.

Methods

We conducted a population-based retrospective cohort study in Saskatchewan between fiscal years 1998/1999 and 2017/2018. This project was part of the “Understanding and advocating for miyo-māhcihowin among Indigenous Peoples living with IBD” project, a patient-oriented research initiative of our IBD Among Indigenous Peoples Research Team.¹²

Patient engagement

Indigenous patient and family advocates contributed to each stage of this project (study conception and design to data analysis and knowledge sharing phases of our research) providing opinions and perspectives which had a considerable weight on the decision-making toward the research process. For example, the study outcomes were chosen in close collaboration with Indigenous patient and family advocates, with 1 advocate having co-presented this work at 3 scientific conferences. The Indigenous patient and family advocates received periodic reports and offered feedback on results and interpretations. We also held research team meetings, had meals and coffee time together and visited their communities.

Data sources

We used administrative health databases from Saskatchewan, including the Person Health Registration System, hospital discharge abstracts, physician claims and prescription medication claims. These databases captured all hospital admissions, outpatient physician visits (except those on-reserve) and prescription medication claims in the province (regardless of the payer). Data were linked using the encrypted unique identifiers, and extracted and analyzed at the Saskatchewan Health Quality Council.

The algorithm developed by Bernstein and colleagues¹⁷ was applied to identify IBD cases using the *International Classification of Diseases* (ICD) codes (for Crohn disease, ICD-10-CA: K50 and ICD-9: 555; for ulcerative colitis, ICD-10-CA: K51 and ICD-9: 556). An IBD case had 5 or more separate IBD contacts within 2 years of health care coverage, or 3 or more IBD contacts when having less than 2 years of health care coverage. This algorithm showed

evidence of good sensitivity (74.4%–89.2%) and specificity (89.8%–93.7%) to identify Crohn disease and ulcerative colitis cases.^{17,18} In addition, we previously used this case definition to determine the epidemiology of IBD among First Nations patients in Saskatchewan.¹² The cases were classified as Crohn disease or ulcerative colitis according to the most frequent diagnosis of IBD.^{12,19,20}

People aged 18 years and older with Saskatchewan Health coverage and meeting the IBD case definition were considered. Only incident IBD cases were included in this study, which were distinguished from prevalent ones by using an 8-year washout period. This 8-year washout period was chosen based on previous IBD epidemiological studies using administrative health data.^{20,21} The self-declared First Nations status variable in the Person Health Registration System was used to classify people with a diagnosis of IBD in 2 groups: patients with First Nations status and those from the general population.²² Previous studies using Saskatchewan administrative databases have used this method to include First Nations patients.^{12,23,24}

Our study outcome was IBD health care utilization assessed by measuring outpatient gastroenterologist visits, colonoscopy, prescription medication claims for IBD, IBD-specific hospital admissions, IBD-related hospital admissions and surgeries for IBD. These outcomes were measured after diagnosis of IBD (i.e., first eligible health care contact of the case definition). We considered the codes of surgeries for IBD in the *Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures* and the *Canadian Classification of Health Interventions*,^{15,25} as well as the codes for colonoscopies. We used the drug identification numbers of IBD medications, including biologic (e.g., infliximab, adalimumab, golimumab, certolizumab, vedolizumab and ustekinumab), immunomodulator (e.g., azathioprine, mercaptopurine and methotrexate) and 5-aminosalicylic acid ([5-ASA]; e.g., mesalamine, sulfasalazine and olsalazine sodium) in the prescription claims data set. Furthermore, we measured the time from the date of diagnosis of IBD to each of the study outcomes. The list of databases and codes can be found in Appendix 1, available at www.cmajopen.ca/content/10/4/E964/suppl/DC1.

Statistical analysis

We matched First Nations patients and those in the general population to a 1:5 ratio based on age and sex; the caliper for age was 5 years. Unadjusted and multivariable Cox proportional regression models were used to identify differences between these groups in outpatient gastroenterologist visits, colonoscopy, medication claims, IBD-specific and -related hospital admissions and surgeries for IBD. Time was measured in years from diagnosis of IBD and terminated by either the time of the first event or censoring. Hazard ratios (HRs) and corresponding 95% confidence intervals (CI) were reported.

Models were adjusted by rural or urban status and diagnosis type. We labelled IBD cases as having urban status with a residential postal code at the date of diagnosis within a census metropolitan area or census agglomeration of 15 000 or more inhabitants.^{20,26} Income quintile, region of residence (i.e., Regina or Saskatoon and surrounding areas, Northern and

Southern Saskatchewan), age at diagnosis of IBD and sex were evaluated as confounding variables. A set of health care utilization variables (i.e., number of visits to a general practitioner, outpatient visits with specialists and IBD medication claims),^{19,27} corticosteroid dependency^{19,28} and Charlson Comorbidity Index²⁹ were measured in the year before a diagnosis of IBD and evaluated as potential confounding variables. A potential confounder was retained in the final model if its inclusion changed coefficients of the First Nations status variable or the other variables in the model by more than 10%.^{30,31} Corticosteroid dependency was defined as having 2 or more prescriptions of oral corticosteroids within 6 months.^{19,28} A stratified analysis was completed by type of disease (ulcerative colitis and Crohn disease).

We used 2 different case definitions of IBD, as a sensitivity analysis, to evaluate variations in the identified associations. Two additional IBD incident cohorts were created using the case definition of Rezaie and colleagues,³² and Benchimol and colleagues²¹ (Appendix 2, available at www.cmajopen.ca/content/10/4/E964/suppl/DC1). After applying the matching procedure used in the main cohort, adjusted HRs were calculated for each study outcome in the different cohorts.

A 2-sided *p* value of less than 0.05 was considered significant. Data analyses were conducted using SAS version 9.4 (SAS Institute).

Ethics approval

Anonymized data from the Saskatchewan Ministry of Health and eHealth were accessed at a Saskatchewan Health Quality Council secure location. Aggregated results were transferred. This study received approval from the Research Ethics Board of the University of Saskatchewan (Beh-REB 977).

Results

We created a matched cohort of 696 incident cases, with 580 IBD cases from the general population and 116 from the First Nations group (Figure 1). Compared with the general population patients diagnosed with IBD, First Nations patients tended to be in the lower income quintiles, live in rural and Northern Saskatchewan and diagnosed with ulcerative colitis (Table 1). The number of events of each outcome are reported in Table 2.

The unadjusted models revealed differences between First Nations patients and patients in the general population in having prescription medication claims for biologic (HR 0.58, 95% CI 0.34–0.99) and 5-ASA (HR 0.68, 95% CI 0.54–0.85) therapies, and differences in having a colonoscopy (HR 0.58, 95% CI 0.47–0.73) and an IBD-related hospital admission (HR 1.45, 95% CI 1.12–1.87) (Table 3).

In the adjusted analyses by rural or urban residence at diagnosis of IBD and diagnosis type, the HR was 48% lower to the first IBD medication claims (HR 0.52, 95% CI 0.41–0.65) and 44% lower to the first 5-ASA medication claims in the First Nations group (HR 0.56, 95% CI 0.45–0.71) compared with the general population. In addition, First Nations patients had 33% higher hazard rates of having an IBD-specific hospital

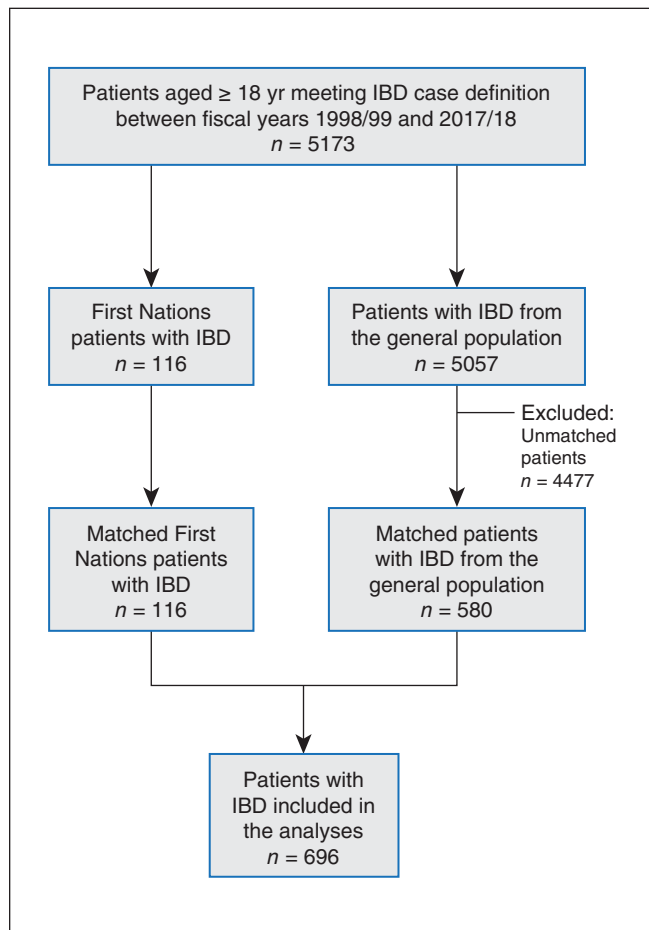


Figure 1: Flow diagram of the study cohort. The caliper used for age was 5 years. Note: IBD = inflammatory bowel disease.

admission (HR 1.33, 95% CI 1.01–1.75) and 55% of having an IBD-related hospital admission (HR 1.55, 95% CI 1.20–2.01). None of the potential confounders changed regression estimates to more than 10% and were not retained in the final model.^{30,31} The distribution of variables measured the year before the diagnosis of IBD and evaluated as potential confounders are presented in Appendix 3, available at www.cmajopen.ca/content/10/4/E964/suppl/DC1.

In the stratified analysis by disease type (Table 3), First Nations patients with Crohn disease and ulcerative colitis had fewer medication claims for IBD (Crohn disease: HR 0.51, 95% CI 0.34–0.76; ulcerative colitis: HR 0.51, 95% CI 0.39–0.68) and 5-ASA claims (Crohn disease: HR 0.56, 95% CI 0.36–0.86; ulcerative colitis: HR 0.54, 95% CI 0.41–0.72) than people with IBD from the general population. Also, differences were observed for IBD-related hospital admissions (HR 1.68, 95% CI 1.14–2.46) in the Crohn disease group.

The sensitivity analysis with the matched cohort using Rezaie and colleagues³² case definition (matched cohort no. 2) included 990 IBD incident cases with 165 from the First Nations group and 825 from the general population. The HRs from matched cohort no. 2 showed similar strengths and directions of associations to those in the main analysis (Appendix 4,

Table 1: Sample characteristics

Characteristic	No. (%) of patients*		
	Total <i>n</i> = 696	General population <i>n</i> = 580	First Nations <i>n</i> = 116
Age at diagnosis of IBD, yr, mean ± SD	41.4 ± 14.8	41.5 ± 14.7	41.2 ± 15.1
Age group, yr			
≤ 30	157 (22.6)	130 (22.4)	27 (23.3)
31–49	346 (49.7)	287 (49.5)	59 (50.9)
≥ 50	193 (27.7)	163 (28.1)	30 (25.9)
Sex			
Female	414 (59.5)	345 (59.5)	69 (59.5)
Male	282 (40.5)	235 (40.5)	47 (40.5)
Income quintile†			
1 (lowest)	101 (15.4)	62 (11.3)	39 (36.1)
2	150 (22.8)	130 (22.6)	20 (18.5)
3	130 (19.8)	113 (20.6)	17 (15.7)
4	156 (23.7)	137 (24.9)	19 (17.6)
5 (highest)	121 (18.4)	108 (19.6)	13 (12.0)
Residence‡			
Rural	239 (34.6)	190 (33.0)	49 (42.2)
Urban	452 (65.4)	385 (67.0)	67 (57.8)
Region of residence§			
Regina, Saskatoon and surrounding	353 (50.8)	305 (52.7)	48 (41.4)
Northern Saskatchewan	146 (21.0)	97 (16.8)	49 (42.2)
Southern Saskatchewan	196 (28.2)	177 (30.6)	19 (16.4)
Diagnosis type			
Crohn disease	342 (49.1)	300 (51.7)	42 (36.2)
Ulcerative colitis	354 (50.9)	280 (48.3)	74 (63.8)
Length of follow-up, yr, mean ± SD	10.7 ± 5.5	11.1 ± 5.4	8.8 ± 5.4

Note: IBD = inflammatory bowel disease, SD = standard deviation.
 *Unless otherwise stated.
 †Data of income quintile not available for all participants (missing values = 38).
 ‡Data of rural or urban residence not available for all participants (missing values = 5).
 §Data of region of residence not available for all participants (missing values = 1).

available at www.cmajopen.ca/content/10/4/E964/suppl/DC1. The matched cohort using Benchimol and colleagues²¹ case definition (matched cohort no. 3) obtained 708 IBD incident cases, with 118 from the First Nations group and 590 from the general population. The analysis using this case definition also attested to the robustness of the study findings (Appendix 5, available at www.cmajopen.ca/content/10/4/E964/suppl/DC1).

Interpretation

First Nations patients had a higher hazard rate of having an IBD-specific and -related hospital admission than patients in the general population. In addition, First Nations patients had fewer prescription claims for IBD medication and 5-ASA compared with patients in the general population.

In agreement with the evidence of increased hospital admission risks for First Nations patients with other chronic conditions (myocardial infarction and congestive heart failure,⁶ and chronic kidney disease⁷), we identified higher hazard rates for hospital admission owing to IBD.

First Nations patients had lower IBD prescription claims than patients in the general population. Some hypotheses to explain this finding could include a shorter follow-up time in the First Nations group which could result in lower medication claims, an association confounded by disease severity, a preference to use traditional medicines, barriers owing to differences in access or coverage criteria for prescription medications and experiences related to systemic racism. Given that we also identified higher IBD-specific and -related hospital admission hazard rates among First Nations patients, these

Table 2: Number of people who ever had the study outcome observed during the approximate 10-year follow-up period*

Outcome	Total n = 696	General population n = 580	First Nations n = 116
Outpatient gastroenterologist visit	579	485	94
Colonoscopy	610	504	106
Prescription claim for IBD	610	518	92
Prescription claim of a biologic	160	145	15
Prescription claim of an IM	264	232	32
Prescription claim of a 5-ASA	560	472	88
IBD-specific hospitalization	349	286	63
IBD-related hospitalization	380	306	74
Surgery for IBD	230	194	36

Note: 5-ASA = 5-aminosalicylic acid, IBD = inflammatory bowel disease, IM = immune modulator.
*No recurrent events were included.

results may suggest that those living with IBD are not receiving appropriate treatments for their disease, resulting in increased rates of hospital admissions. Perhaps owing to lack of trust and racism in the health care systems, Indigenous people often access health care when they are experiencing more severe and complex conditions.³ This late health care access is also related to delays in diagnosis and lack of follow-up, leading Indigenous people to have worse health outcomes.³

These results call for a change in the context of the social determinants of health, the inequities that exist within the health care systems and who has and who does not have access to a more streamlined, optimal health care.^{33,34} A potential explanation for First Nations patients not having prescription medication claims for IBD involves systemic challenges that are embedded in racist protocols and processes in health care. For example, First Nations patients may have faced a lack of coverage by the Non-Insured Health Benefits program, lack of understanding about the coverage and claim process, or simply rejection of coverage,³⁵ which is more limited and restrictive than provincial coverage for the general population. The Non-Insured Health Benefits program generally has more restrictive criteria to access biologics both in terms of

Table 3: Measures of association between First Nation status (reference general population) and each of the study outcomes*

Outcomes	Stratified analysis					
	Full-group analysis n = 696		Crohn disease n = 342		Ulcerative colitis n = 354	
	Unadjusted HR (95% CI)	Adjusted HR (95% CI)†	Unadjusted HR (95% CI)	Adjusted HR (95% CI)‡	Unadjusted HR (95% CI)	Adjusted HR (95% CI)§
Outpatient gastroenterologist visit	1.10 (0.88–1.37)	1.13 (0.90–1.41)	0.95 (0.65–1.39)	0.99 (0.67–1.45)	1.22 (0.92–1.61)	1.20 (0.91–1.59)
Colonoscopy	1.25 (1.01–1.54)¶	1.14 (0.92–1.41)	1.19 (0.83–1.72)	1.20 (0.83–1.73)	1.11 (0.86–1.45)	1.11 (0.85–1.44)
Prescription claim for IBD	0.58 (0.47–0.73)¶	0.52 (0.41–0.65)¶	0.53 (0.35–0.78)¶	0.51 (0.34–0.76)¶	0.52 (0.39–0.68)¶	0.51 (0.39–0.68)¶
Prescription claim of a biologic	0.58 (0.34–0.99)¶	0.65 (0.38–1.11)	0.67 (0.33–1.38)	0.67 (0.32–1.37)	0.61 (0.28–1.35)	0.62 (0.28–1.36)
Prescription claim of an IM	0.70 (0.48–1.01)	0.79 (0.55–1.15)	0.68 (0.40–1.15)	0.69 (0.40–1.17)	0.93 (0.55–1.57)	0.93 (0.55–1.58)
Prescription claim of a 5-ASA	0.68 (0.54–0.85)¶	0.56 (0.45–0.71)¶	0.60 (0.39–0.92)¶	0.56 (0.36–0.86)¶	0.54 (0.41–0.72)¶	0.54 (0.41–0.72)¶
IBD-specific hospitalization	1.24 (0.94–1.63)	1.33 (1.01–1.75)¶	1.55 (1.04–2.30)¶	1.50 (1.00–2.23)	1.18 (0.80–1.72)	1.17 (0.80–1.71)
IBD-related hospitalization	1.45 (1.12–1.87)¶	1.55 (1.20–2.01)¶	1.74 (1.19–2.54)¶	1.68 (1.14–2.46)¶	1.42 (1.00–2.01)	1.41 (1.00–2.00)
Surgery for IBD	1.13 (0.79–1.62)	1.14 (0.80–1.64)	0.95 (0.52–1.72)	0.93 (0.51–1.70)	1.32 (0.84–2.07)	1.30 (0.83–2.05)

Note: 5-ASA = 5-aminosalicylic acid, CI = confidence interval, HR = hazard ratio, IBD = inflammatory bowel disease, IM = immune modulator.
*Unless stated otherwise.
†Models adjusted by rural or urban status, and diagnosis type (n = 691).
‡Crohn disease group, models adjusted by rural/urban status (n = 339).
§Ulcerative colitis group, models adjusted by rural/urban status (n = 352).
¶Bold values denote significant results.

the number of conventional therapies that were unsuccessful, and the duration of time on other therapies before failure of treatment or intolerance can be documented, compared with provincial coverage criteria for the general population.

These results speak to more action in the light of the Truth and Reconciliation Commission of Canada Calls to Action, antiracist practices in the health care system and proper addressing of the root causes of the health care inequities for First Nations patients with IBD. Further studies should continue evaluating access to IBD care (including navigation and cultural safety in health care systems), medication use and disease severity among First Nations patients with IBD. Despite the Royal Commission on Aboriginal Peoples and the Truth and Reconciliation Commission of Canada that aimed to improve the health of Indigenous people, there is still a long way to go to promote cultural safety in health care.^{36–38} Patient navigation could also help First Nations patients to obtain early access to health care services and help reduce health care disparities.^{39,40}

According to the study results, Indigenous patient and family advocates in the research team highlighted the need to improve access to specialized care for First Nations patients living with IBD. The Indigenous patient and family advocates considered that First Nations communities were more exposed to a westernized diet and need more traditional and spiritual care along with westernized medicine. Indigenous patient and family advocates also suggested that poor housing and water and food insecurity on reserves should be considered when studying IBD among First Nations patients. Indigenous patient and family advocates stressed that racism and poor living conditions leading to poorer mental health (e.g., stress, anxiety and depression) might also place First Nations patients living with IBD at a greater disadvantage. First Nations patients with IBD could advocate for themselves with more awareness and education about this disease.

Lessons learned from working with Indigenous patient and family advocates

We evidenced the promotion of reconciliation and healing through bonding with the Indigenous patient and family advocates, appreciation and learning about Indigenous cultures and the prioritization of the Indigenous patient and family advocates' perspectives and recommendations. We also ensured an inclusive and collaborative research environment. The research team learned that there are different ways forward in advocating for the health of First Nations patients and that the study results have application in the light of systematic racism and oppression. The COVID-19 pandemic restrictions limited in-person interactions; however, research team members communicated regularly by way of videoconference, telephone calls and text messages.

Limitations

Misclassification bias can be a potential issue when using health administrative data to study chronic diseases, such as IBD,^{20,41} with mistakes originating from data entry.⁴¹ A validated case definition that required multiple health care contacts with the

diagnosis of IBD was applied to address this potential issue.¹⁷ A sensitivity analysis was also completed using 2 additional validated IBD case definitions.^{21,32} Moreover, the First Nations status variable could account for self-declared First Nations patients in the administrative health databases. Another limitation comes from using Indigenous-specific health information in health systems. Data may not have been collected in a culturally appropriate way and may be compromised owing to factors such as misclassification errors and nonresponse bias, leading to an underestimation of Indigenous health issues.⁴² Finally, disease severity and disease management data were not available in administrative health data and may confound IBD health care utilization and medication claims. We considered multiple health care utilization variables in the year before diagnosis of IBD as proxy measures of disease severity;^{19,27} however, these variables did not have an impact on the observed associations.

Conclusion

We identified First Nations patients diagnosed with IBD had higher hazard rates of IBD-specific and -related hospital admissions than patients in the general population diagnosed with IBD. Additionally, inverse associations between First Nations status and having prescription medication claims for IBD and for 5-ASA were found. These associations might reflect a barrier to access IBD medications, contributing to a higher hazard rate for IBD-specific or -related hospital admissions in the First Nations group. Further studies should continue to evaluate access to IBD care among First Nations patients and other Indigenous people living with IBD to improve care and address health disparities.

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