Inflammatory Bowel Diseases, 2024, **XX**, 1–14
https://doi.org/10.1093/ibd/izae010
Advance access publication 16 February 2024
Original Research Articles - Clinical

Health Services Utilization and Specialist Care in Pediatric Inflammatory Bowel Disease: A Multiprovince Population-Based Cohort Study

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Received for publication: October 26, 2023. Editorial Decision: January 1, 2024

Background: Patterns of health services utilization among children with inflammatory bowel disease (IBD) are important to understand as the number of children with IBD continues to increase. We compared health services utilization and surgery among children diagnosed <10 years of age (Paris classification: A1a) and between 10 and <16 years of age (A1b).

Methods: Incident cases of IBD diagnosed <16 years of age were identified using validated algorithms from deterministically linked health administrative data in 5 Canadian provinces (Alberta, Manitoba, Nova Scotia, Ontario, Quebec) to conduct a retrospective cohort study. We compared the frequency of IBD-specific outpatient visits, emergency department visits, and hospitalizations across age groups (A1a vs A1b [reference]) using negative binomial regression. The risk of surgery was compared across age groups using Cox proportional hazards models. Models were adjusted for sex, rural/urban residence location, and mean neighborhood income quintile. Province-specific estimates were pooled using random-effects meta-analysis.

Results: Among the 1165 (65.7% Crohn's) children with IBD included in our study, there were no age differences in the frequency of hospitalizations (rate ratio [RR], 0.88; 95% confidence interval [CI], 0.74-1.06) or outpatient visits (RR, 0.95; 95% CI, 0.78-1.16). A1a children had fewer emergency department visits (RR, 0.70; 95% CI, 0.50-0.97) and were less likely to require a Crohn's-related surgery (hazard ratio, 0.49; 95% CI, 0.26-0.92). The risk of colectomy was similar among children with ulcerative colitis in both age groups (hazard ratio, 0.71; 95% CI, 0.49-1.01).

Conclusions: Patterns of health services utilization are generally similar when comparing children diagnosed across age groups.

Lay Summary

Among 1165 children with inflammatory bowel disease, health services utilization was similar for children diagnosed <10 years of age and those diagnosed ≥10 years of age, except younger children had fewer emergency department visits and Crohn's disease–related surgeries.

Key Words: gastroenterologist care, health administrative data, distributed network analysis, Crohn's disease, ulcerative colitis

Key Messages

What is already known?

- The incidence of very early onset inflammatory bowel disease (IBD) is rising.
- Children diagnosed with IBD at different ages have different phenotypes.

What is new here?

- The frequency of hospitalizations, outpatient visits, and gastroenterologist visits is similar for children diagnosed <10 years of age and between 10 and <16 years of age; younger children have fewer emergency department visits and fewer Crohn's disease–related surgeries.

How can this study help patient care?

- As rates of pediatric IBD continue to climb around the world, our data provide important information for health system planners to ensure that healthcare resources will be sufficient to care for the growing number of children with IBD.

Introduction

The incidence and prevalence of pediatric-onset inflammatory bowel disease (IBD) are rising globally, and Canada has among the highest rates of pediatric IBD in the world.[1] The incidence of IBD in Canada is increasing most rapidly among children, particularly among those <5 years of age at diagnosis.[2] The number of children with IBD in Canada doubled between 2008 and 2018 and is expected to double again by 2030.[3] IBD presenting in childhood is different from adult-onset IBD. Children typically have more extensive disease and a predominantly inflammatory phenotype.[4,5] In particular, children with onset of IBD younger than 10 years of age (defined as A1a by the Paris modification of the Montreal classification)[6] are noted to have a predominantly colonic phenotype,[6] increased frequency of monogenic origin,[7] and differences in health services utilization patterns.[8] These differences are associated with higher direct healthcare costs in children with IBD compared with adults.[9]

We have previously characterized health services used by children with IBD in Ontario, Canada.[10,11] We found decreasing rates of hospitalization and surgeries associated with an increased outpatient visit rate[10] and increasing care provided by pediatric specialists over time.[11] This study expanded our analysis to 5 Canadian provinces, comprising 79.1% of the Canadian population,[12] to describe health services use before and after diagnosis with childhood-onset IBD. In addition, we compared health services utilization and surgical rates in children diagnosed prior to 10 years of age (A1a) with those diagnosed at older age (A1b).

Methods

Study Design and Data Sources

We conducted a population-based retrospective cohort study of pediatric-onset IBD, diagnosed prior to 16 years of age, using health administrative data from 5 Canadian provinces (Alberta, Manitoba, Nova Scotia, Ontario, and Quebec). All provinces have government-funded universal healthcare covering all eligible residents (>99% of the population). All provinces collect health administrative data on physician claims and hospitalizations. Alberta, Ontario, and Quebec additionally have data on all emergency department (ED) visits. Individual-level data within each province were linked deterministically using a unique encrypted identification number based on provincial health card numbers. Details of the databases used in each province are outlined in Supplementary Table 1. In Ontario, all databases are maintained by ICES, an independent, non-profit research institute whose legal status under Ontario's health information privacy law allows it to collect and analyze healthcare and demographic data, without consent, for health system evaluation and improvement. In Manitoba, all administrative health data are maintained by Manitoba Health and the study utilized the population-based cohort of persons with IBD in the University of Manitoba IBD Epidemiology Database. In Nova Scotia, the administrative health data were made available through Health Data Nova Scotia. In Alberta, the administrative health data were made available through Alberta Health Services. In Quebec, data were made available through the Regie De L'Assurance

Maladie du Québec. Datasets are available to researchers in an uncleaned and unedited format.[13]

Provincial privacy regulations prevent individual-level data from being shared across provincial borders. To obtain estimates encompassing all participating provinces, we conducted a distributed network analysis. This approach involves creating analytic code in one province, adapting this code to produce estimates from identical analyses in other participating provinces, and obtaining overall estimates by pooling province-specific results via meta-analysis.[2,14] Validation of this method has demonstrated that meta-analysis of pooled estimates produces similar results to individual-level data analysis in multivariable regression models.[15] For all provinces, any outcomes experienced by fewer than 6 individuals could not be reported for privacy reasons.

Identifying Children with IBD

Previously validated province-specific algorithms based on International Classification of Diseases–Ninth Revision (ICD-9) and International Classification of Diseases–Tenth Revision–Canadian enhancement (ICD-10-CA) codes for Crohn's disease (CD) (ICD-9: 555; ICD-10: K50) and ulcerative colitis (UC) (ICD-9: 556; ICD-10: K51) were used to identify cases of pediatric-onset IBD and differentiate between CD and UC.[16-19] Details of each algorithm are described in Supplementary Table 1. To differentiate incident from prevalent cases, all children were required to have a 3-year washout period without any diagnostic code for IBD prior to the cluster of diagnostic codes required by each province's case definition; this method was previously validated to distinguish incident from prevalent cases with >95% accuracy.[17] No washout period was required for individuals with continuous eligibility for healthcare coverage in the same province from birth until IBD diagnosis. The date of IBD diagnosis was considered to be the first healthcare encounter with a diagnostic code for IBD within the cluster of diagnostic codes qualifying them as an IBD case.

Children in Alberta were diagnosed between fiscal years (FYs) (April 1 to March 31) 2005 to 2014 and followed until 2016. Children in Manitoba were diagnosed between FY1999 and FY2010 and followed until 2013. Children in Nova Scotia were diagnosed between FY1999 and FY2010 followed until 2010. Children in Ontario were diagnosed between FY1999 and FY2010 and followed until 2012. Children in Quebec were diagnosed between FY1999 and FY2007 and followed until 2009. Study start and end dates varied due to differing data availability across provinces.

Outcomes

All outcomes and the time frame for which they were assessed are outlined in Supplementary Table 2.

Postdiagnosis Health Services Utilization

We evaluated IBD-specific and IBD-related outpatient visits, ED visits, and hospitalizations occurring on or after the date of IBD diagnosis. IBD-specific encounters had a diagnostic code for CD (ICD-9: 555; ICD-10: K50) or UC (ICD-9: 556; ICD-10: K51). IBD-related encounters included IBD-specific encounters, as well as encounters with a diagnostic code for a sign, symptom, or extraintestinal manifestation of IBD. Example signs and symptoms included abnormal weight loss and abdominal pain. Examples of extraintestinal manifestations included arthropathies and primary sclerosing cholangitis. A full list of signs, symptoms, and extraintestinal manifestations included in our list of IBD-related healthcare encounters and their corresponding diagnostic codes is provided in Supplementary Table 3.[10,11,14,20] For both IBD-specific and IBD-related hospitalizations, one of the specified diagnostic codes must have been listed as a most responsible diagnosis, pre- or postadmission comorbidity, or diagnosis contributing to a transfer between institutions. Only hospitalizations with a length of stay of at least 2 days were included in order to exclude hospitalizations for colonoscopy bowel preparation or medication infusions.

Outpatient visits, ED visits, and hospitalizations were modeled as the number of events per person per year between diagnosis and the end of follow-up. If a person had multiple encounters of the same type on the same day, only one was counted. No other restrictions were placed on the frequency of events a person could have and there was no minimum time between healthcare encounters. All provinces were included for analyses of outpatient visits and hospitalizations. ED visits were included only for Ontario, Quebec, and Alberta due to lack of province-wide data on ED visits in Manitoba and Nova Scotia.

Specialist Care

We determined the number of IBD-specific and IBD-related outpatient visits per person per year to a gastroenterologist (pediatric or adult) during the first 4 years following their diagnosis. In addition, we determined the proportion of children that had an IBD-specific or IBD-related visit to a gastroenterologist and the number of IBD-specific and IBD-related gastroenterologist visits within the first 2 years and first 4 years following diagnosis.

Gastroenterologists were identified based on their registered specialty and/or the number of endoscopies that they performed per year (see Supplementary Table 1 for province-specific definitions).[14,21] Physicians without sufficient endoscopy codes in a single year but with a sufficient number of codes in the previous or following year were considered gastroenterologists. We combined pediatric and adult gastroenterologists due to challenges in differentiating between pediatric and adult gastroenterologists in some provinces. Alberta and Quebec were excluded from the specialist care outcomes because accurate information on physician specialty was not included in their physician claims databases.

Health Services Utilization in the Year Before Diagnosis

We identified prediagnosis outpatient, ED, and hospital health services utilization in the year prior to diagnosis with a diagnostic code suggestive of a subsequent diagnosis of IBD. The list of diagnostic codes that were indicative of a subsequent diagnosis of IBD was determined by a survey of gastroenterologists who were experts in IBD diagnosis and treatment.[14] Codes were rated on a 5-point Likert scale with 5 being most indicative of a future IBD diagnosis. Those codes with a mean rank ≥4 were deemed as most likely related to the subsequent diagnosis of IBD and included in our outcome (Supplementary Table 4).[14] Separate lists of diagnostic codes were generated for CD and UC.

We determined the number of healthcare encounters associated with one of these codes in the year prior to diagnosis. Outpatient visits, hospitalizations, and ED visits were combined in a single outcome because there were very few hospitalizations and ED visits prior to IBD diagnosis.

Surgery

Children requiring intestinal resection (for CD) and colectomy (for UC) were identified using previously validated procedural codes from hospitalization records (Supplementary Table 5).[22,23] Only the first surgery was included in our analysis. We report the percentage of children requiring surgery within 5 years of IBD diagnosis and using a time-to-event approach in regression analyses. We excluded Manitoba from our age comparison of the risk of intestinal resection in CD and Manitoba and Quebec from our age comparison of the risk of colectomy in UC due to the small number of surgeries among patients, which resulted in convergence issues with regression models.

Demographic Characteristics

This study compared individuals diagnosed <10 years of age (A1a) and those diagnosed 10 to <16 years of age (A1b), as per the age groupings of the Paris modification of the Montreal Classification,[6] and allowing for minimum 2 years of follow-up for all patients under the care of pediatric gastroenterologists. Transfer of care to adult gastroenterologists in Canada typically occurs around a person's 18th birthday. Other variables included in the regression models were sex (male/female), before-tax mean neighborhood household income quintile (a validated proxy for individual socioeconomic status),[24] and living in a rural or urban residence location (see Supplementary Table 1 for definitions). Both neighborhood income and rural/urban residence location were defined at the date of IBD diagnosis.

Statistical Analysis

Characteristics of patients included in each provincial cohort were described using mean ± SD (continuous variables) or frequency and percentage (categorical variables).

In each province, we calculated the mean number of IBD-specific and IBD-related outpatient visits (overall and specifically with a gastroenterologist), ED visits, and hospitalizations for all children combined, then stratified by age at diagnosis (A1a and A1b). We also calculated the mean number of prediagnosis healthcare encounters in the year prior to diagnosis. Province-specific means were then pooled using random-effects meta-analysis to account for expected heterogeneity across provincial healthcare systems.[25]

The proportion of children in each province with at least 1 gastroenterologist visit within 2 and 4 years of diagnosis were reported for all children combined, then stratified by age at diagnosis. Due to small numbers of children <10 years of age requiring surgery, the age-specific percentage of children requiring surgery could not be reported. When between 1 and 5 children experienced an outcome (eg, surgery) in a single province, privacy regulations prevent reporting of the actual number of events. When this occurred, we randomly assigned a number of events between 1 and 5 to allow for that province's data to be pooled in the meta-analysis. Proportions were pooled using random intercept logistic regression model, akin to a random-effects meta-analysis with a logit transformation,[26] then converted to percentages for ease of interpretation.

Province-specific regression models were fitted to compare outcomes among individuals diagnosed with IBD <10 years of age (A1a) and 10 to <16 years of age (A1b [reference group]). The mean number of healthcare encounters (outpatient visits, ED visits, hospitalizations, and gastroenterologist outpatient visits) in the 2 age groups were compared using negative binomial regression to account for the overdispersion observed with Poisson models; rate ratios (RRs) and their 95% confidence intervals (CIs) were estimated. Time to surgery was compared using Cox proportional hazards regression; hazard ratios (HRs) and their 95% CIs were estimated. The likelihood of having seen a gastroenterologist was compared using logistic regression within 2 and 4 years of IBD diagnosis; odds ratios (ORs) and their 95% CIs were estimated. For all types of regression models, an effect estimate (RR, HR, or OR) of 1 indicates no difference in the outcome when comparing A1a and A1b children. Values >1 indicate that the outcome occurred more frequently (Poisson regression), occurred sooner (Cox proportional hazards regression), or was more likely (logistic regression) among A1a children relative to A1b children; values <1 indicate the opposite. All regression models were adjusted for sex, mean neighborhood income quintile, and rural/urban residence location. Province-specific effect estimates obtained from regression models were then pooled using random-effects meta-analysis.[15] For all meta-analyses, between-province heterogeneity was quantified using the I^2 statistic.[27] I^2 corresponds to the proportion of the variance in the outcome that can be attributed to true between-province differences, rather than to random error; higher I^2 values are indicative of greater between-province heterogeneity.

Primary data analysis in each province was conducted in SAS version 9.4 (SAS Institute). Meta-analyses were performed in R version 4.2.2 (R Foundation for Statistical Computing) using the meta package, and forest plots were created using the metafor package.[28–30]

Sensitivity Analysis

Because data on ED visits were only available for 3 provinces (Alberta, Ontario, and Quebec), we repeated the meta-analysis of prediagnosis healthcare encounters excluding those provinces without ED data. This included recalculating the pooled means (overall and stratified by age at diagnosis) and the comparison across ages at diagnosis.

Ethical Considerations

This study was approved by the Research Ethics Boards at the Children's Hospital of Eastern Ontario, IWK Health Centre, Montreal Jewish General Hospital, University of Alberta, University of Calgary, and the University of Manitoba. This study was reviewed for privacy concerns by Alberta Health Services, Manitoba Health's Information Privacy Committee, Health Data Nova Scotia, ICES, and the Commission d'Accès à l'Information du Québec.

Results

The cohort included 5124 children diagnosed with IBD, of whom 1165 (22.7%) were diagnosed before 10 years of age. Nearly two-thirds (65.7%) of our cohort had CD (Table 1).

Table 1. Characteristics of study participants.

	Alberta		Manitoba		Nova Scotia		Ontario		Quebec		Overall	
	A1a (<10 y)	A1b (10 to <16 y)	A1a (<10 y)	A1b (10 to <16 y)	A1a (<10 y)	A1b (10 to <16 y)	A1a (<10 y)	A1b (10 to <16 y)	A1a (<10 y)	A1b (10 to <16 y)	A1a (<10 y)	A1b (10 to <16 y)
Children	208 (29.6)	495 (70.4)	47 (20.8)	179 (79.2)	74 (23.6)	240 (76.4)	607 (22.9)	2049 (77.1)	229 (18.7)	996 (81.3)	1165 (22.7)	3959 (77.3)
Age at diagnosis, y[a]	5.4 ± 2.8	13.0 ± 1.6	7.4 ± 1.7	13.0 ± 1.6	6.5 ± 2.8	13.4 ± 1.6	6.5 ± 2.4	13.0 ± 1.6	7.6 ± 2.1	13.6 ± 1.7	6.7 ± 0.4	13.2 ± 0.1
Type of IBD												
CD	93 (44.7)	314 (63.4)	25 (53.2)	104 (58.1)	43 (58.1)	159 (66.3)	292 (48.1)	1278 (62.4)	194 (84.7)	863 (86.6)	647 (55.5)	2718 (68.7)
UC	63 (30.3)	154 (31.1)	22 (46.8)	75 (41.9)	26-30 (35.1-40.5)[b]	68 (28.3)	258 (42.5)	644 (31.4)	29 (12.7)	113 (11.3)	398-402 (34.2-34.5)[b]	1054 (26.6)
IBDU	52 (25.0)	27 (5.5)	N/A	N/A	1-5 (1.4-6.8)[b]	13 (5.4)	57 (9.4)	127 (6.2)	6 (2.6)	20 (2.0)	116-120 (10.0-10.3)[b]	187 (4.7)
Female	95 (54.3)	212 (42.8)	25 (53.2)	79 (44.1)	33 (44.6)	105 (43.8)	262 (43.2)	863 (42.1)	102 (44.5)	443 (44.5)	517 (44.4)	1702 (43.0)
Residence location[c]												
Urban	165 (79.3)	398 (80.4)	37 (78.7)	140 (78.2)	51 (68.9)	164 (68.3)	548 (90.3)	1823 (89.0)	175 (78.8)	782 (80.6)	976 (84.3)	3307 (84.1)
Rural	43 (20.7)	97 (19.6)	10 (21.3)	39 (21.8)	23 (31.1)	76 (31.7)	59 (9.7)	225 (11.0)	47 (21.2)	188 (19.4)	182 (15.7)	625 (15.9)
Mean neighborhood income quintile[c]												
1 (lowest)	27 (13.2)	88 (18.0)	7-11[b]	19 (10.7)	17 (23.0)	57 (23.8)	72 (11.9)	265 (13.0)	48 (21.6)	154 (15.9)	171-175[b]	583 (14.9)
2	37 (18.0)	105 (21.5)	10 (21.3)	30 (16.9)	14 (18.9)	41 (17.1)	113 (18.7)	343 (16.8)	35 (15.8)	160 (16.5)	209 (18.1)	679 (17.3)
3	42 (20.5)	99 (20.3)	1-5[b]	37 (20.8)	15 (20.3)	43 (17.9)	130 (21.5)	406 (19.9)	25 (11.3)	190 (19.6)	213–217[b]	775 (19.8)
4	35 (17.1)	80 (16.4)	13 (27.7)	40 (22.5)	11 (14.9)	44 (18.3)	143 (23.7)	479 (23.4)	56 (25.2)	255 (26.3)	258 (22.4)	898 (22.9)
5 (highest)	64 (31.2)	116 (23.8)	12 (25.5)	52 (29.2)	17 (23.0)	55 (22.9)	146 (24.2)	551 (27.0)	58 (26.1)	211 (21.8)	297 (25.8)	985 (25.1)

Values are n (%), mean ± SD.
Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; IBDU, inflammatory bowel disease type unclassifiable; N/A, not applicable; UC, ulcerative colitis.
[a]Pooled mean ± SE for overall data.
[b]Actual number suppressed due to privacy regulations concerning small cell counts.
[c]Number of study participants in each category may not add up to the total number of study participants due to missing data.

Postdiagnosis Health Services Utilization

Hospitalizations

The mean annual number of IBD-specific hospitalizations following IBD diagnosis among children included in our cohort was 0.19 (95% CI, 0.17-0.21) with high heterogeneity across provinces (I^2 = 74%) (Figure 1A). The mean number of hospitalizations per year did not differ between the A1a and A1b groups (RR, 0.88; 95% CI, 0.73-1.06; I^2 = 62%). Hospitalization rates and the differences across age groups were similar in CD and UC (Supplementary Figure 1).

The mean annual number of IBD-related hospitalizations among children was 0.21 (95% CI, 0.19-0.23) with high between-province heterogeneity (I^2 = 78%) (Figure 1A). The frequency of IBD-related hospitalizations did not differ for children in the A1a and A1b groups (RR, 0.95; 95% CI, 0.87-1.05; I^2 = 0%). Findings were similar in children with CD and UC (Supplementary Figure 1).

ED Visits

In the 3 provinces with data on ED visits (Alberta, Ontario, and Quebec), children and adolescents had a mean of 0.17 (95% CI, 0.07-0.27) IBD-specific and 0.29 (95% CI, 0.19-0.39) IBD-related ED visits per year (Figure 1B). Heterogeneity between provinces was high for both IBD-specific (I^2 = 99%) and IBD-related (I^2 = 97%) ED visits. Those in the A1a group had fewer IBD-specific visits (RR, 0.70; 95% CI, 0.50-0.97; I^2 = 80%). The magnitude of the association comparing IBD-related visits across age groups was similar but not statistically significant (RR, 0.76; 95% CI, 0.57-1.01; I^2 = 85%). Findings were similar in CD (Supplementary Figure 2A). A1a children with UC had fewer IBD-specific (RR, 0.66; 95% CI, 0.54-0.82; I^2 = 0%) and IBD-related (RR, 0.71; 95% CI, 0.60-0.85; I^2 = 0%) ED visits (Supplementary Figure 2B).

Outpatient Visits

Children with IBD averaged 3.2 (95% CI, 1.9-4.4; I^2 = 99.6%) IBD-specific and 3.9 (95% CI, 2.3-5.5; I^2 = 99.7%) IBD-related outpatient visits per year (Figure 1C). There were no differences in the number of IBD-specific outpatient visits across age groups in the analysis combining all types of IBD (RR, 0.95; 95% CI, 0.78-1.16; I^2 = 86%) and in the analysis limited to children with CD (RR, 1.10; 95% CI, 0.95-1.27; I^2 = 66%) (Supplementary Figure 3A). Children with UC in the A1a group had fewer IBD-specific outpatient visits than those in the A1b group (RR, 0.90; 95% CI, 0.82-0.98; I^2 = 0%) (Supplementary Figure 3B). There were no age differences in the number of IBD-related outpatient visits (RR, 1.01; 95% CI, 0.89-1.14; I^2 = 71%); this finding was consistent across both types of IBD.

Surgery

Within 5 years of diagnosis of CD, 11.9% of children (95% CI, 7.2%-18.9%; I^2 = 92%) required an intestinal resection or colectomy. A1a children with CD were less likely to undergo surgery compared with those in the A1b group (HR, 0.49; 95% CI, 0.26-0.92; I^2 = 40%) (Figure 2). This observation was limited to 4 provinces (Alberta, Nova Scotia, Ontario, and Quebec), as the Manitoba data were too sparse for model convergence.

Overall, 10.9% (95% CI, 6.5%-17.8%; I^2 = 61%) of children with UC required a colectomy within 5 years of diagnosis. This risk of colectomy was similar in both age groups (HR, 0.71; 95% CI, 0.49-1.01; I^2 = 0%) (Figure 2). This observation was limited to 3 provinces (Alberta, Nova Scotia, and Ontario), as there were too few children with UC undergoing colectomy in Manitoba and Quebec for model convergence.

Prediagnosis Health Services Utilization

Children diagnosed with IBD had a mean of 1.03 (95% CI, 0.40-1.66) healthcare encounters in the year prior to diagnosis that were most likely related to subsequent IBD diagnosis, with high heterogeneity between provinces (I^2 = 99.6%) (Figure 3). A1a children had fewer encounters than those in the A1b group (RR, 0.80; 95% CI, 0.73-0.89; I^2 = 0%). There were no differences between age at diagnosis and the number of prediagnosis healthcare encounters when analyzing CD and UC separately (Supplementary Figure 4). Quebec was excluded from the analysis comparing the frequency of these visits across age groups in children with UC due to a small number of A1a cases. The results of a sensitivity analysis limited to the 3 provinces with ED data (Alberta, Ontario, and Quebec) yielded similar results (Supplementary Figure 5).

Gastroenterology Specialist Care

Approximately 90% of children with IBD had ≥1 IBD-related outpatient visit with a gastroenterologist within 2 years of diagnosis, with high heterogeneity across provinces (Figure 4). There were no statistically significant differences in the odds of having seen a gastroenterologist across the 2 age groups (OR, 0.69; 95% CI, 0.45-1.05; I^2 = 0%). Findings were similar when extending follow-up to 4 years after diagnosis (Figure 4) and in children with UC (Supplementary Figure 6). Children diagnosed with CD before 10 years of age were less likely to have visited a gastroenterologist within 2 years of diagnosis (OR, 0.48; 95% CI, 0.24-0.95; I^2 = 0%) but not within 4 years of diagnosis (OR, 0.52; 95% CI, 0.22-1.22; I^2 = 0%) compared with older children.

Children with IBD averaged 5.2 (95% CI, 3.4-6.9; I^2 = 97.8%) IBD-specific visits with gastroenterologists in their first year following diagnosis, with gradual decreases in the annual number of visits with time (within the second year: 4.1; 95% CI, 3.1-5.0; I^2 = 96.1%; within the third year: 3.6; 95% CI, 2.9-4.4; I^2 = 95%; within the fourth year: 3.3; 95% CI, 2.7-4.0; I^2 = 94%) (Figure 5A). There were no differences in the number of IBD-specific outpatient visits among children in the A1a and A1b groups in the second year after diagnosis (RR, 0.97; 95% CI, 0.91-1.02; I^2 = 0%) or in the fourth year after diagnosis (RR, 0.96; 95% CI, 0.91-1.02; I^2 = 0%).

Children with IBD averaged 5.6 (95% CI, 3.8-7.5; I^2 = 99%) IBD-related outpatient visits to a gastroenterologist in the first year following their IBD diagnosis, with the average number of visits decreasing with each year after diagnosis (Figure 5B). The frequency of IBD-related visits to gastroenterologists did not differ across age at diagnosis. No differences across ages were noted when comparing IBD-specific and IBD-related visits to gastroenterologists when analyzing CD and UC separately (Supplementary Figure 7).

Discussion

In this population-based study of health services use among children with IBD in Canada, we found that utilization is generally similar among those diagnosed before 10 years of age

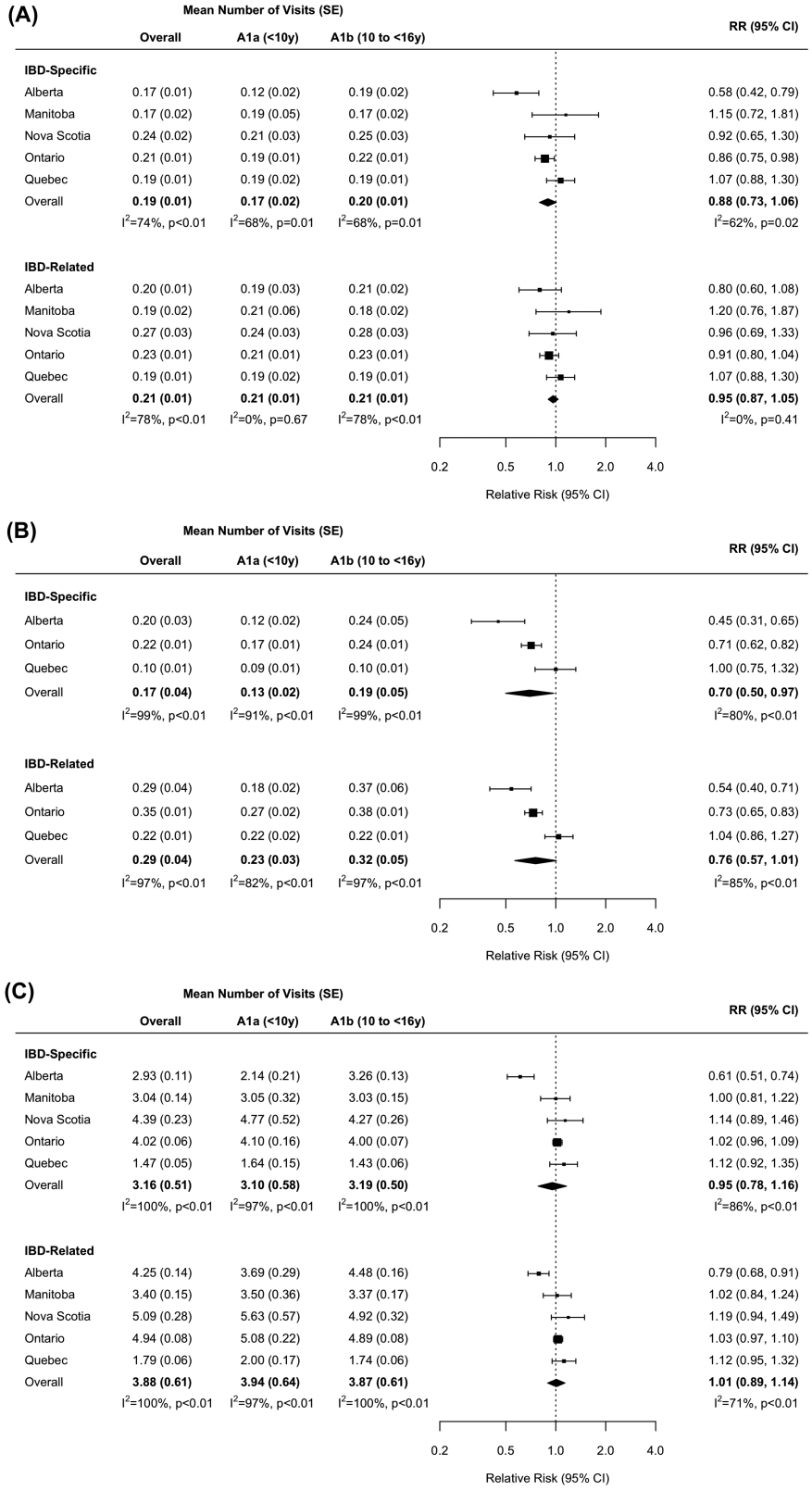

Figure 1. Rate ratios (RRs) comparing the mean number of inflammatory bowel disease (IBD)–specific and IBD-related (A) hospitalizations, (B) emergency department visits, and (C) outpatient visits per year among children and adolescents diagnosed with IBD at <10 years of age (A1a) and between 10 and <16 years of age (A1b). CI, confidence interval.

(A1a) and those diagnosed between 10 and <16 years of age (A1b). The exception was that children diagnosed with IBD in the A1a group had fewer ED visits relative to those in the A1b group—a finding that was specific to children with UC. Despite similar utilization of health services, children with UC in the A1a group had numerically fewer colectomies and

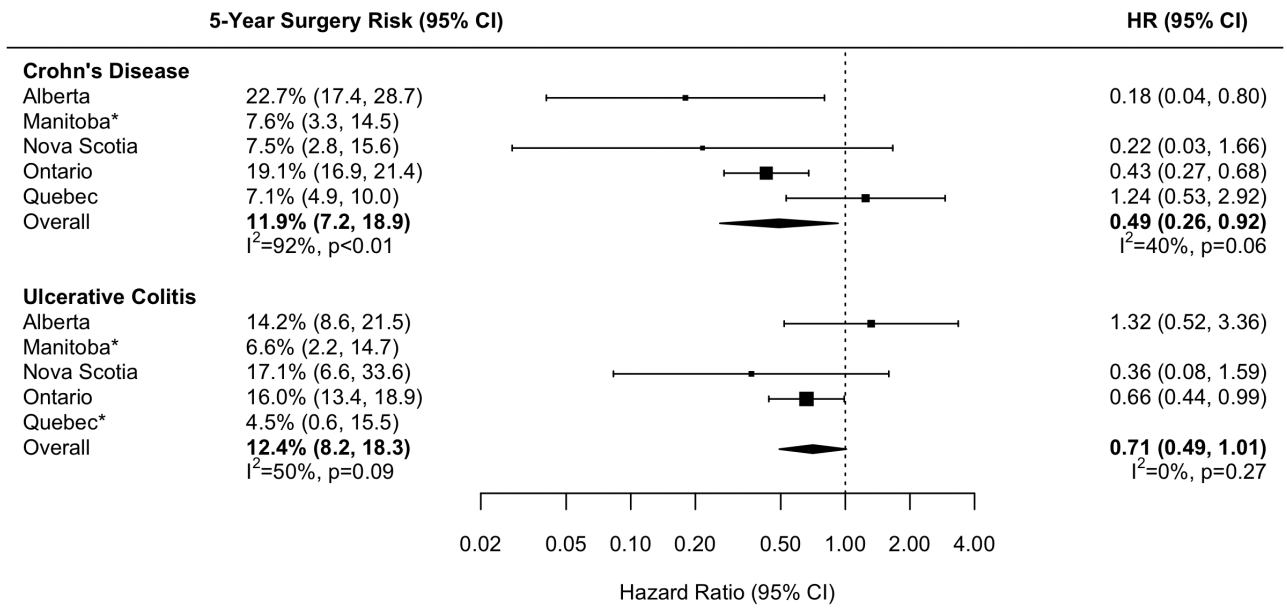

Figure 2. Hazard ratios (HRs) comparing the age-related risk of intestinal resection or colectomy in children and adolescents with Crohn's disease and colectomy in children and adolescents with ulcerative colitis. *Models comparing the risk of surgery across age groups did not converge. These provinces are included in the pooled risk of surgery within 5 years of diagnosis but not in the pooled HR. CI, confidence interval.

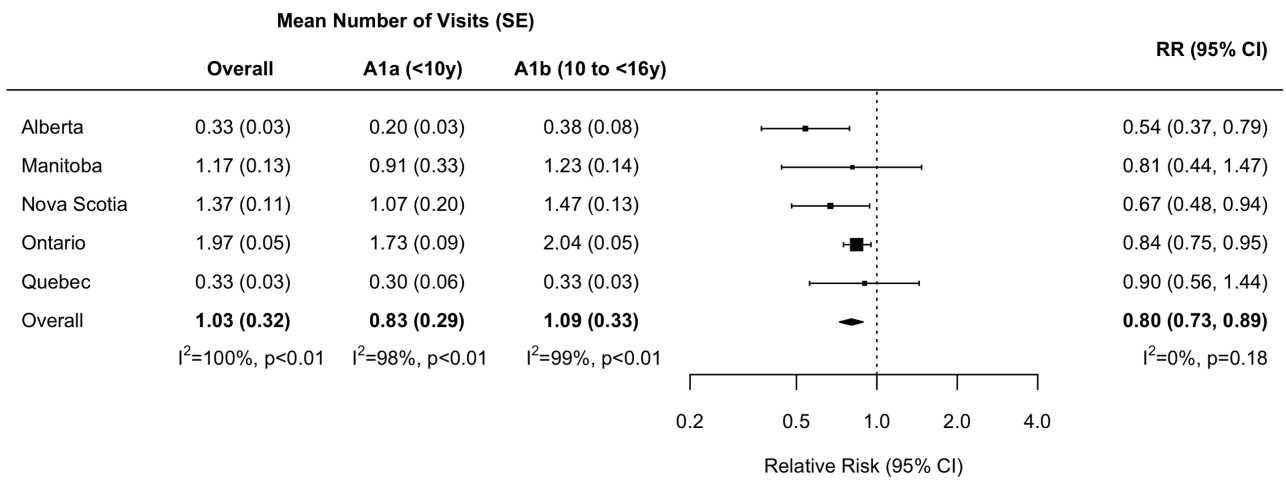

Figure 3. Rate ratios (RRs) comparing the mean number of healthcare visits (outpatient, emergency department, or hospitalization) with a diagnostic code most likely related to a subsequent inflammatory bowel disease (IBD) diagnosis in the year prior to IBD diagnosis among children and adolescents diagnosed with IBD at <10 years of age (A1a) and between 10 and <16 years of age (A1b). CI, confidence interval.

children with CD in the A1a group were significantly less likely to require surgery than older children (ie, A1b group).

On average, children had 1 potentially IBD-related visit before diagnosis although children diagnosed before 10 years of age had fewer healthcare encounters in the year prior to their IBD diagnosis compared with those diagnosed after 10 years of age. This may reflect differing signs and symptoms of typical IBD phenotypes in the 2 groups. For example, the colonic phenotype that predominates both CD and UC patients in the younger A1a group leads to earlier signs of IBD (eg, bloody diarrhea) in these younger children, as compared with signs and symptoms relating to small bowel or patchy presentations of older children, which may prompt more rapid recognition by primary care providers and referral to gastroenterologists.[31] As opposed to adults with IBD who receive care from a spectrum of gastroenterologists with expertise in recognizing IBD, the minimal delay for children suggests that there is reasonably rapid access to the expert centers where pediatric IBD care is provided in these 5 provinces.

Most of our cohort received care from gastroenterologists, including those in rural and remote regions. This implies good access to specialist care, at least in the early period following diagnosis. Unfortunately, our databases could not accurately distinguish care provided by pediatric and adult gastroenterologists in every province. In Canada, there are relatively few pediatric gastroenterologists, and they are primarily located in tertiary care specialty pediatric hospitals in larger cities. In contrast, adult gastroenterologists are distributed across a variety of care settings, ranging from community practices to tertiary care hospitals. We previously found that children living in rural and urban areas were equally likely to have visited a gastroenterologist;

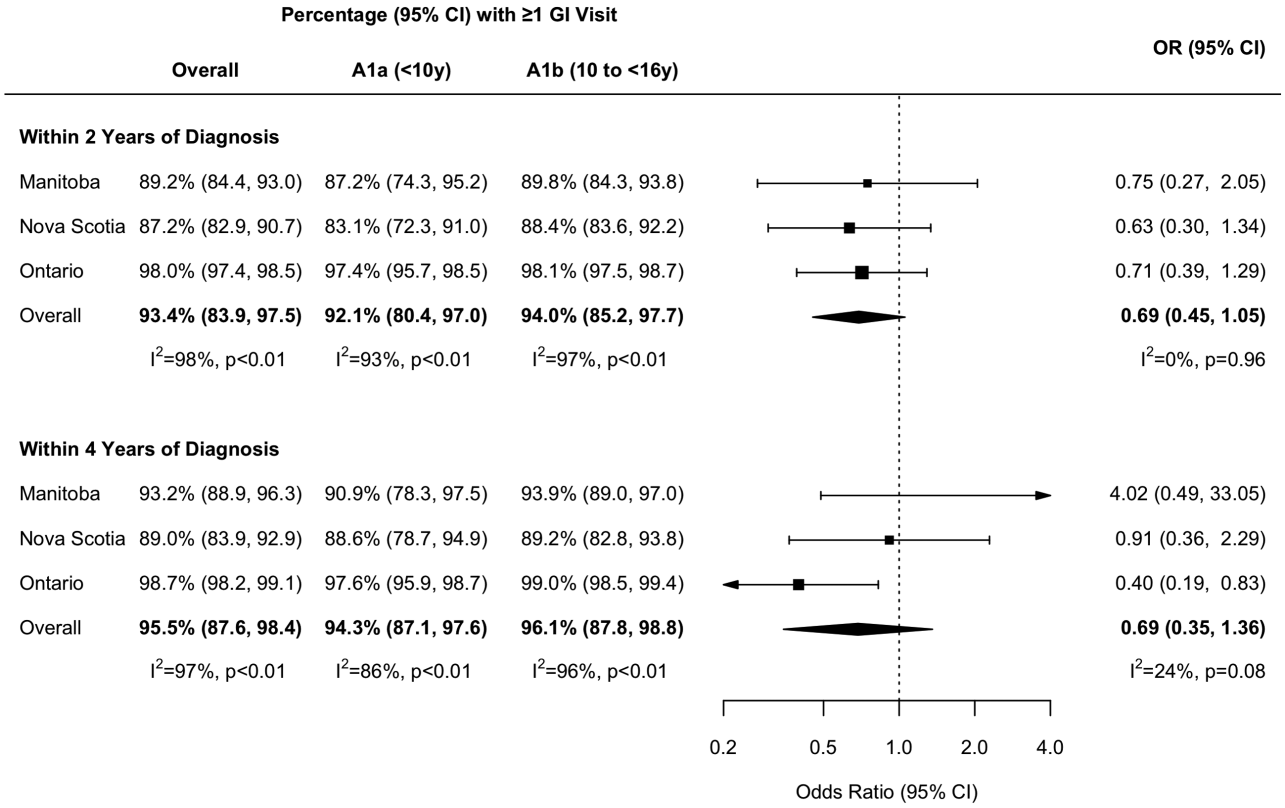

Figure 4. Odds ratios (ORs) comparing the likelihood of having an inflammatory bowel disease (IBD)–related visit to a gastroenterologist (GI) within 2 and 4 years of IBD diagnosis among children and adolescents diagnosed with IBD at <10 years of age (A1a) and between 10 and <16 years of age (A1b). CI, confidence interval.

however, the frequency of visits to gastroenterologists were reduced among children living in rural communities relative to their peers living in urban areas.[14] While an adult study demonstrated improved IBD outcomes in IBD patients treated by a gastroenterologist,[21,32] there may be sacrifices made when compared with an approach in which primary care physicians (PCP) coordinate care. An American study demonstrated trade-offs in care coordination of children with IBD with a gastroenterologist as their main provider, compared with those with a PCP as their main provider.[33] Those with a gastroenterologist were less likely to receive important health services such as regular primary care visits and mental healthcare. Therefore, the coordination of care of children with IBD between PCPs, gastroenterologists, and other allied healthcare professionals remains of paramount importance.

Although we generally did not find that age was associated with health services utilization, disparities in access and provision of health services may still exist. We noted substantial heterogeneity between provinces in the meta-analyses (as denoted by the I^2 value), which may indicate variation in care across provinces. This was particularly true for hospitalizations (resulting from lower rates in Alberta), ED visits, and prediagnosis visits. Some of this heterogeneity may be due to differences in coding systems or databases used. For example, ED visits were determined in Ontario by both the National Ambulatory Care Reporting System and physician billing databases, whereas in Alberta and Nova Scotia, only the National Ambulatory Care Reporting System contained ED visit data. However, this would not explain the lower hospitalization rates seen in Alberta, as hospitalization data came from the standardized national dataset collected by professional coders and submitted to the Canadian Institute for Health Information. Some of the heterogeneity may be due to differences in care provision patterns and disparities. Despite universal health coverage, each province is responsible for the local administration of healthcare. As a result, there are differences in healthcare policy and models of care that may contribute to variation between provinces. Furthermore, we previously noted disparities in the care of children with IBD from low- and high-income homes.[20] Future research should assess the source of this heterogeneity, and whether true variation in care exists. If so, variation should be addressed as a method of improving the quality of care.[34,35]

The finding that children with IBD diagnosed <10 years of age were less likely to undergo surgery was previously noted in a population-based study from Ontario,[8] as well as internationally. Our Ontario study demonstrated that the lower surgery rates were driven by children <6 years of age at diagnosis (very early onset IBD [VEO-IBD]), while children 6 to 10 years of age had similar rates to adolescents. Our findings are different from a recent population-based study from Israel, which demonstrated no difference in surgical rates in patients with VEO-IBD compared with those with older-onset pediatric disease.[36] However, this study indicated that rates of surgery were much higher with the infantile-onset form of the disease. This points to the possibility that the A1a group is heterogeneous in terms of surgical risk, with potentially higher rates in infants and lower rates in older children. Unfortunately, we were not able to examine patients with VEO-IBD as a distinct

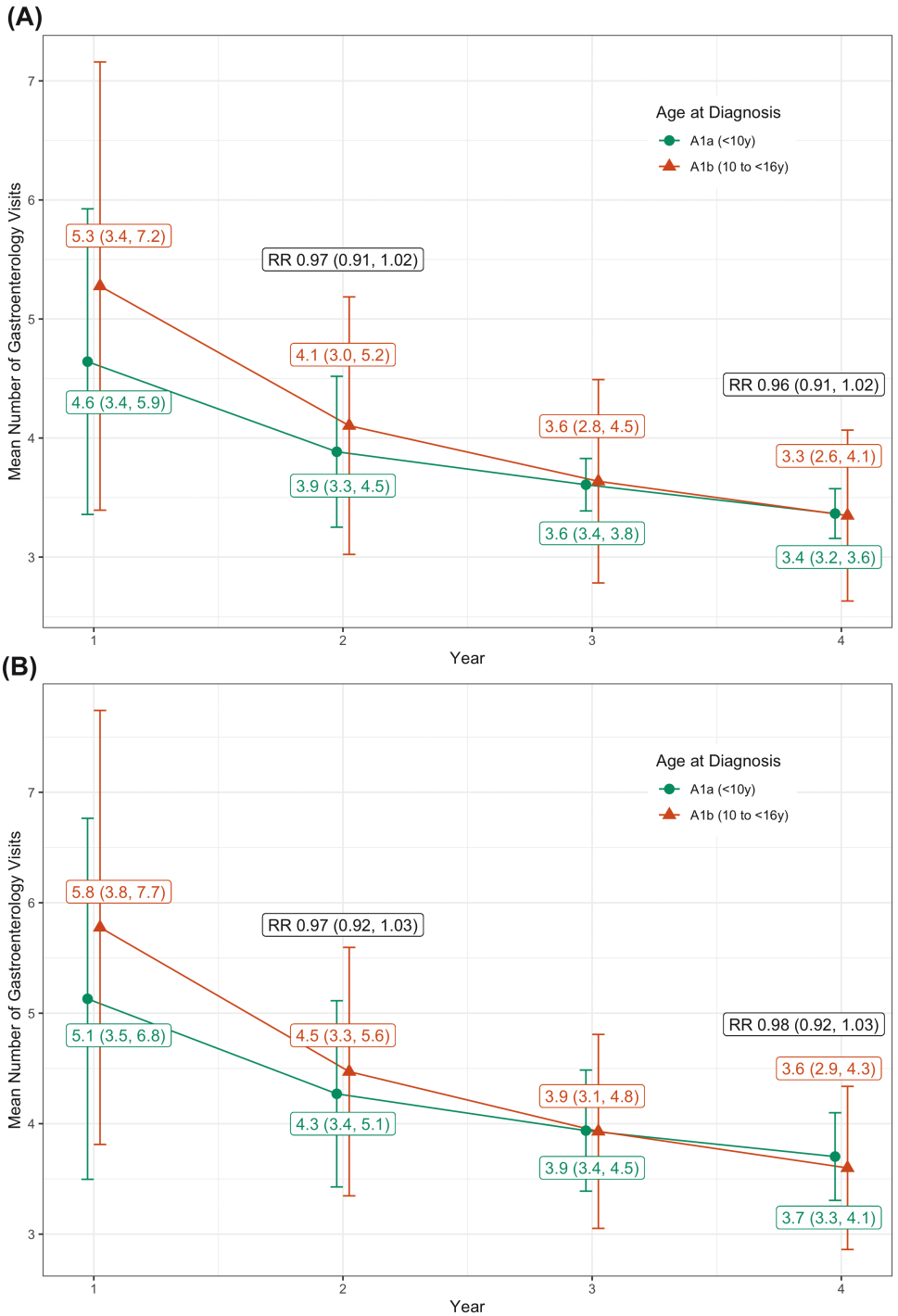

Figure 5. The pooled mean (95% confidence interval) number of (A) inflammatory bowel disease (IBD)–specific and (B) IBD-related visits to a gastroenterologist during the first 4 years following IBD diagnosis among children diagnosed with IBD at <10 years of age (A1a; green) and between 10 and <16 years of age (A1b; red). Pooled rate ratios comparing the mean number of visits during the second and fourth years following diagnosis are depicted in black font.

group due to the small number of patients and the rarity of surgical outcomes in some provinces. The reason for lower surgical rates in A1a patients remains uncertain. This may be due to less severe disease in this group (refuted by the similar hospitalization rates), or differences in phenotype. Supporting the latter hypothesis, the rates were lower in CD patients but not statistically significantly different in UC patients. Because colonic disease predominates in the A1a group, physicians may be more hesitant to request colectomy in CD patients, as opposed to limited small bowel resection in older CD patients. The study from Israel found differences in treatment choice in younger IBD patients, with lower rates of biologic and immunomodulator use, and higher rates of 5-aminosalicylic acid use.[36] However, a recent North American cohort study found similarly high rates of anti-tumor necrosis factor utilization in VEO-IBD patients compared with rates reported for other pediatric patients in the literature.[37] Future research should examine decision making among those caring for

young children with IBD to understand why different treatment choices are made, and whether the best possible care is being provided to young children with IBD.

The strengths of this study include its large sample size and population-based nature, using the health administrative data of approximately 80% of the Canadian population. In addition, we used validated algorithms to identify children with IBD, and distinguish those with CD and UC. However, there are some important weaknesses to note. Our findings may not apply to all regions. However, Canada has a universal health system; therefore, we would expect that our description of health services use would most closely apply to regions where financial considerations do not impede access to healthcare. All studies using health administrative data are subject to misclassification bias, and the coding used for health services utilization (particularly prediagnosis codes), outcomes, and specialist care have not been validated. Coding differences across provinces may have resulted in the heterogeneity observed in the meta-analyses. Our follow-up period included the period during which adolescents were transitioning from pediatric to adult IBD care. We have previously demonstrated higher outpatient and ED visits following the transfer of care to an adult gastroenterologist; the frequency of hospitalization was not impacted by this transfer.[38] Thus, we do not expect the transition period to bias our comparisons of health services utilization of children diagnosed in the A1a and A1b groups. Differences in data availability resulted in slight differences in the study periods across the 5 provinces. Combined with the evolution of practice patterns, these differences in data availability may have contributed to between-province heterogeneity. However, the evolution of practice patterns likely did not differ across ages at diagnosis, so we do not expect this to confound our findings. Finally, population-based and comprehensive medication data were not available in Ontario, Nova Scotia, and Quebec (which only collect complete prescription data for people ≥65 years of age and those receiving government-funded income-based pharmacare during the study period); therefore, we were unable to describe the treatments received by children with IBD, which may have contributed to the age group and interprovincial differences noted. This will be the subject of a future study using data from provinces with complete prescription databases (Alberta, Manitoba, Saskatchewan, and British Columbia).

Conclusions

In summary, this study of health services use of children with IBD in Canada found that few differences in rates of health system contacts exist in children diagnosed before 10 years of age as compared with older children. However, these younger children were less likely to undergo surgery, had fewer ED visits, and had short prediagnosis lag times. While some variation across provinces existed, this may be due to either differences in care or data heterogeneity. The finding of generally consistent care across provinces and age groups is encouraging, and reflects the universal nature of Canada's health system and the tight network of pediatric IBD specialists in Canada engaged in coordinated research and clinical care,[31,39] concentrated at specialized tertiary care centers. Furthermore, our data provide vital information for health system planning globally, particularly in regions with increasing incidence and prevalence of pediatric IBD.

Supplementary data

Supplementary data is available at *Inflammatory Bowel Diseases* online.

Acknowledgments

E.I.B. holds the Northbridge Financial Corporation Chair in Inflammatory Bowel Disease, a joint Hospital-University Chair between the University of Toronto, The Hospital for Sick Children, and the SickKids Foundation. The authors appreciate the contributions from the Canadian Children IBD Network, a national collaborative funded by the CH.I.L.D. Foundation. This study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC). Parts of this material are based on data and information compiled and provided by the Ontario Ministry of Health and Canadian Institute for Health Information. The analyses, conclusions, opinions and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred. An abstract based on the data included in this manuscript was presented at Canadian Digestive Diseases Week (Halifax, Nova Scotia, Canada) in 2023.

Author Contributions

Study design and conceptualization: M.E.K., A.B., M.W.C., A.M.G., G.G.K., G.C.N., A.R.O., C.N.B., S.S., H.S., E.I.B. Funding acquisition: A.B., M.W.C., A.M.G., G.G.K., G.C.N., A.R.O., C.N.B., E.I.B. Acquisition of data and/or statistical analysis: M.E.K., A.B., G.G.K., A.R.O., H.S., C.N.B., SGF, S.S., Z.N., S.C., Y.C., J.C., C.F., E.I.B. Interpretation of results: M.E.K., A.B., M.W.C., A.R.O., H.S., G.G.K., T.A.S., D.R.M., K.J., A.M.G., W.E.M., L.E.T., G.C.N., J.L.J., S.K.M., C.N.B., LML, J.N.P.-S., T.J.B.D., S.S., E.I.B. Drafting of manuscript: M.E.K., E.I.B. Critical revision of manuscript: A.B., M.W.C., A.R.O., H.S., G.G.K., T.A.S., D.R.M., K.J., A.M.G., W.E.M., L.E.T., G.C.N., J.L.J., S.K.M., C.N.B., L.M.L., J.N.P.-S., T.J.B.D., S.S., SGF, Z.N., C.S., Y.C., J.C., C.F., E.I.B. Final approval of manuscript: M.E.K., A.B., M.W.C., A.R.O., H.S., G.G.K., T.A.S., D.R.M., K.J., A.M.G., W.E.M., L.E.T., G.C.N., J.L.J., S.K.M., C.N.B., L.M.L., J.N.P.-S., T.J.B.D., S.S., SGF, Z.N., C.S., Y.C., J.C., C.F., E.I.B. Overall guarantor of the work: E.I.B.

Funding

This work was supported by a Grant-in-Aid of Research from Crohn's and Colitis Canada, a Foundation Grant from the Canadian Institutes of Health Research (grant reference number 201409FDN-333131-FDN-CECC-164898), and a Project Scheme Operating Grant from the Canadian Institutes of Health Research (grant reference number PJT-162393). Neither funding agency had a role in the design, conduct, interpretation of results, or conclusions of this study. M.E.K. was supported by a Post-Doctoral Fellowship Award from the Canadian Institutes of Health Research, Canadian Association of Gastroenterology, and Crohn's and Colitis Canada and a Mitacs Elevate Post-Doctoral Fellowship. D.R.M. is supported in part through a University of Ottawa Faculty of Medicine Distinguished Clinical Research Chair

in Pediatric Inflammatory Bowel Disease Award. T.J.B.D. is the Canadian Cancer Society Chair in Cancer Primary Prevention. E.I.B. was supported by a New Investigator Award from the Canadian Institutes of Health Research, Canadian Association of Gastroenterology, and Crohn's and Colitis Canada and also by the Career Enhancement Program of the Canadian Child Health Clinician Scientist Program. This study was supported by the ICES, which is funded by an annual grant from the Ontario Ministry of Health and the Ministry of Long-Term Care. The analyses, conclusions, opinions and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred.

Conflicts of Interest

A.B. has participated in advisory boards for AbbVie, Janssen, Takeda, McKesson, BioJamp, Bristol Myers Squibb; served on the speakers panel for Janssen, Takeda, and AbbVie; and participated in educational activities supported by Viatris, Fresenius Kabi, and Amgen. M.W.C. has received speaker fees from AbbVie. A.R.O. has served on advisory boards for AbbVie Canada, Janssen Canada, and Amgen; has received unrestricted educational grants from AbbVie Canada; and is co-owner of the copyright for PUCAI and the IMPACT questionnaire; and his site is involved with clinical trials for AbbVie, Pfizer, Takeda, Eli Lilly, and BMS. H.S. has served on advisory boards or consulted for Pendopharm, AbbVie Canada, Amgen Canada, Organon Canada, Eli Lilly Canada, Roche Canada, Sandoz Canada, Takeda Canada, Bristol Myers Squibb, and Guardant Health Inc; and has received research funding for an investigator-initiated study from Pfizer. G.G.K. has received honoraria for speaking or consultancy from AbbVie, Amgen, Janssen, Pfizer, Sandoz, and Pendopharm; has received grants for research from Ferring and for educational activities from AbbVie, Bristol Myers Squibb, Ferring, Fresenius Kabi, Janssen, Pfizer, Takeda; and shares ownership of a patent (TREATMENT OF INFLAMMATORY DISORDERS, AUTOIMMUNE DISEASE, AND PBC. UTI Limited Partnership, assignee. Patent WO2019046959A1. PCT/CA2018/051098. 7 Sept. 2018). D.R.M. is co-owner of Biotagenics Inc. K.J. has served on advisory boards for AbbVie Canada, Janssen Canada, Amgen, Merck Canada, Mylan Pharmaceuticals, Viatris, and McKesson Canada; served on the speakers bureau for and received investigator-initiated research support from AbbVie Canada and Janssen Canada; and has stock options for Engene. A.M.G. is past holder of the Northbridge Financial Corporation Chair in Inflammatory Bowel Disease, a joint Hospital-University Chair between the University of Toronto, The Hospital for Sick Children, and the SickKids Foundation; has received research support from AbbVie Canada; is co-owner of copyright for the Pediatric Ulcerative Colitis Activity Index and the TUMMY-UC; has served on the advisory board member or as a consultant for AbbVie, Amgen, Bristol Myers Squibb, Janssen, Lilly, Merck, Pfizer, and Takeda; and has received speaker fees from AbbVie, Janssen, and Takeda. L.E.T. has received research funding from AbbVie Canada, Takeda Canada, Sandoz Canada, Amgen Canada, Gilead Canada, Roche Canada and Pfizer Canada, and has been on Advisory Boards for Janssen Canada, AbbVie Canada, Takeda Canada, Pfizer Canada, Merck Canada, Roche Canada, Sandoz Canada, Organon Canada, Fresenius Kabi Canada, Eli Lilly Canada, and Amgen Canada. G.C.N. has served on the advisory board for AbbVie Canada and Takeda Canada. J.L.J. has received honoraria for speaking and consulting for AbbVie, Janssen, Pfizer, Shire, and Takeda. S.K.M. has participated in advisory board meetings for AbbVie, Janssen, Takeda, Pfizer, Shire and Ferring; and as a speaker at educational events sponsored by Janssen, AbbVie, and Pfizer. C.N.B. is supported by the Bingham Chair in Gastroenterology; has served on advisory Boards for AbbVie Canada, Amgen Canada, Bristol Myers Squibb Canada, Eli Lilly Canada, Ferring Canada, JAMP Pharmaceuticals, Pendopharm Canada, Janssen Canada, Sandoz Canada, Takeda Canada, and Pfizer Canada; has received educational grants from AbbVie Canada, Amgen Canada, Bristol Myers Squibb Canada, Eli Lilly Canada, Organon Canada, Pfizer Canada, Takeda Canada, and Janssen Canada; has served on the speakers panel for AbbVie Canada, Janssen Canada, Pfizer Canada, and Takeda Canada; and has received research funding from AbbVie Canada, Amgen Canada, Pfizer Canada, Sandoz Canada, and Takeda Canada. E.I.B. has served as a consultant for the Dairy Farmers of Ontario and McKesson Canada for matters unrelated to medications used to treat inflammatory bowel disease and for the Canadian Agency for Drugs and Technology in Health. All other authors disclose no conflicts.

Data Availability

This is a multiprovince study whereby province-specific datasets are provided to investigators in each province and analyzed locally. Province-specific data availability statements are provided.

- Alberta: To comply with Alberta's Health Information Act and in order to minimize the possibility of unintentionally sharing information that can be used to reidentify private information, the dataset cannot be made publicly available. The data from the present study are held securely in de-identified form on a secure server at the University of Calgary and was provided by the Alberta Strategy for Patient Oriented Research Support Unit. Legal data-sharing agreements between the researchers, Alberta Strategy for Patient Oriented Research Support Unit, and the data providers (eg, healthcare organizations, and government) prohibit researchers from making the dataset publicly available. The underlying the analytic code is available from the authors upon request.
- Manitoba: This study is based in part on de-identified data provided by Manitoba Health, and the data used in these analyses are owned by the government of Manitoba. We were given permission to use the data to conduct the analysis. However, we do not have permission to share the data. Researchers interested in replicating results, can apply to the ministry of health to access the data through the Provincial Health Research Privacy Committee. Instructions can be found at https://www.rithim.ca/phrpc-overview. The interpretation and conclusions contained herein are those of the authors and do not necessarily represent the views of the Government of Manitoba.
- Nova Scotia: This study is based in part on de-identified data provided by Health Data Nova Scotia. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Nova Scotia. Neither the Government of Nova Scotia nor Health Data Nova Scotia expressed any opinion in relation to this study.

- Ontario: The dataset from the Ontario portion of this study is held securely in coded form at ICES. While legal data sharing agreements between ICES and data providers (eg, healthcare organizations and government) prohibit ICES from making the dataset publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at www.ices.on.ca/DAS (email: das@ices.on.ca). The full dataset creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification.
- Quebec: The data used for the Quebec portion of this study is de-identified and is provided by the Regie de d'Assurance Maladie du Québec. The use of data for research was approved by the Commission d'Accès à l'Information du Québec, which oversees the protection of privacy. Legal data sharing agreements prohibit making the dataset publicly available. Researchers wishing access to the dataset would have to make a formal request to the Institut de la Statistique du Québec. The interpretations and conclusions in this study are those of the researchers and not those of the Quebec government.

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