

Models of Care for Inflammatory Bowel Disease: A National Cross-sectional Survey to Characterize the Landscape of Inflammatory Bowel Disease Care in Canada

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Background: Collaborative care models improve inflammatory bowel disease (IBD) patient outcomes, yet little is known about the capacity or available resources to deliver such model of care in Canada. We aimed to describe the structure and process characteristics of clinical care delivery models for IBD across Canada, including the number of collaborative care centers.

Methods: A cross-sectional study was conducted between November 2017 and October 2018 through an online survey. This survey was distributed to gastroenterologists at community and academic centers across Canada who provide care for IBD patients. Comparisons between collaborative and non-collaborative centers were analyzed using chi-squares or *t*-tests. Descriptive statistics of respondent demographics were also generated.

Results: Seventy-two gastroenterologists from 62 unique IBD centers completed the survey. A total of 7 unique collaborative centers and 55 unique non-collaborative centers were identified. There were significant differences between collaborative and non-collaborative centers in some aspects of access to IBD care, patient assessment and referral process, and patient education and empowerment. Notably, very few centers had processes for implementing and evaluating evidence-based clinical pathways, and auditing quality indicators.

Conclusions: Our findings identify areas for improving the quality of IBD care in Canada. Expanding the number of and access to collaborative care centers in Canada is needed, in addition to increased focus on patient education, communication, and implementation of evidence-based care pathways.

Lay Summary

Collaborative care is an important innovation in providing quality inflammatory bowel disease (IBD) care, yet few collaborative care centers exist in Canada. More collaborative care centers focusing on patient education, communication, and implementing evidence-based care are needed to improve IBD patient care.

Key Words: inflammatory bowel disease, quality improvement, collaborative care

Introduction

Inflammatory bowel disease (IBD), including Crohn's disease and ulcerative colitis, is a chronic, immune-mediated, intestinal inflammatory condition of unclear etiology.¹ People with IBD require multifaceted and holistic care to manage symptoms and disease activity, and monitor for disease recurrence.² However, providing comprehensive, holistic patient care is challenging. In Canada, where the incidence and prevalence of IBD are among the highest globally, the health

care systems are challenged to provide access to needed services and supports.³ Therefore, finding effective and efficient models to deliver quality health care to IBD patients is imperative. Conceptualizing and delivering quality IBD care have been at the forefront of clinical practice and research in Canada. In 2012, the Emerging Practice in IBD Collaborative (EPIC) developed a list of 9 quality indicators (QIs) to guide a minimum standard of IBD care and management in Canada.⁴ QIs can serve as quantitative endpoints

to measure quality of care. Promoting Access and Care Through Centres of Excellence (PACE) further expanded the list of QIs to 45 to transform IBD care in Canada.⁵ Access to a range of multidisciplinary clinicians and allied health professionals was identified as 1 QI by IBD patients during this process.⁵

Globally, many institutions have adopted integrated collaborative care models to provide best-practice management of IBD patients. Collaborative care centers involve physicians, allied health professionals, and patients working together to define problems, set goals, plan care, teach self-management, provide support, and maintain follow-up.⁶ According to Mikocka-Walus et al, these models share commonalities pertaining to patient access to care, patient assessment, and patient education.⁷ A global survey of IBD health care providers concluded the ideal service was a multidisciplinary center where patients could access IBD nurses and routine psychological and nutritional assessments.⁸ Adoption of collaborative care models is increasing internationally with attention given to specialized multidisciplinary IBD care, such as pediatric, obstetric, and surgical care.⁹

Multidisciplinary IBD care also improves patient outcomes. Studies of dedicated IBD services show reduced hospital admissions, wait times for surgical procedures, and patient steroid and opioid use.^{10–17} According to patients, multidisciplinary care improves their quality of life and helps maintain a positive patient–physician relationship.¹⁴ Recent research also indicates that IBD patients prefer and want to access multidisciplinary care.^{18,19} Although these studies appear to provide strong evidence of improved patient care, they also have limitations. Most are single center, retrospective reviews of inpatient IBD care. This limits their applicability to a larger patient population as well as outpatients. Retrospective studies of care models are also difficult to interpret given rapidly changing treatment guidelines and practice standards, which can affect patient outcomes.

It is evident collaborative care centers can deliver high-quality, cost-effective IBD patient care. Little is known, however, about the resourcing or capacity in centers across Canada to deliver care through a collaborative care center. According to Mikocka-Walus et al, Winnipeg, Manitoba has an IBD care model including gastroenterologists, IBD nurses, basic scientists, and other supportive staff.⁸ Saskatoon, Saskatchewan also has an established multidisciplinary IBD center for patients and family members.^{15,16} While some Canadian IBD centers have adopted collaborative models, more information is needed to understand the current landscape of IBD care models across Canada. A better understanding of this landscape will allow us to determine where advocacy and resourcing is most required to improve access to multidisciplinary IBD care across Canada.

In this study, we aimed to describe the structure and process characteristics of clinical IBD care delivery models across Canada. Specifically, we aimed to (1) determine the number of collaborative IBD care centers in Canada; (2) understand the infrastructure and processes used by these centers; (3) describe how IBD patients access these centers, what IBD practitioners and allied health professionals work within or are affiliated with these centers, and the process and structure of referral pathways and clinical visits for patients within IBD centers.

Materials and Methods

Study Design and Sample

We completed a cross-sectional study between November 2017 and August 2018 to survey Canadian gastroenterologists at both community and academic IBD centers across Canada. Multiple methods of contact were attempted to maximize response rate. The contact information for each gastroenterologist in Canada was acquired using a database provided by Scott's Directories (<https://www.scottsdirectories.com>). The database was generated from the Canadian Medical Directory, which has contact information for practicing physicians across Canada by specialty. This database was cross-referenced with gastroenterologists listed by the Royal College of Physicians and Surgeons. All participant information was coded to maintain anonymity. In October 2017, all Canadian gastroenterologists on the contact list were invited to participate in the survey via fax which contained study information, a unique study code and a link to the online survey. A link to a non-conditional incentive of a \$5 bookstore e-gift certificate was provided. A total of 3 survey broadcasts were sent to maximize response rate: (1) GI institutional division heads were emailed a survey link and asked to distribute to division members; (2) The survey was posted on the Canadian Association of Gastroenterology (CAG) website from November 2017 to August 2018; and (3) An e-blast of the survey was sent out to CAG physician members. Approximately 704 gastroenterologists were contacted out of estimated 784–848 luminal gastroenterologists who practice in Canada.²⁰ Participation in this study was voluntary and responses were anonymized using the unique study codes provided to participants.

Questionnaire

The questionnaire was developed and administered using Novi Survey software. It employed the principles of Choi and Pak²¹ to reduce bias, as well as Dillman's Tailored Design methodology.²² The question format included single answer, multiple answers, and open ended. The questionnaire items were derived from the PACE QIs and divided into 6 sections: (1) IBD clinic information, (2) safety and quality improvement, (3) access to care, (4) patient assessment and referral process, (5) patient education and empowerment, and (6) respondent demographics. Individuals who were ineligible to complete the survey were asked to complete demographic information only. Pilot testing was performed among 3 gastroenterologists and 2 nurse practitioners at the QEII Health Sciences Centre (Halifax, Nova Scotia), who provided feedback on content, formatting, and readability.

Definitions

Collaborative IBD care models were defined as those in which access to the following (at a minimum) was mandatory: a gastroenterologist and/or IBD-ologist, IBD nurse (practitioner or registered nurse), and allied health care professionals (a dietician and a clinical health psychologist). Questionnaire items about QIs were classified and grouped according to those identified by EPIC and PACE for IBD care and management in Canada (eg, access to care, patient assessment and referral, patient empowerment and education, and safety and quality improvement).^{4,5} Unique centers were identified based on postal code and clinic type.

Table 1. Sociodemographic information.

	Collaborative care N ^b = 10	Non-collaborative care N = 62	Overall N = 72	P ^a
Sex, <i>n</i> (%)				
Female	4 (40)	14 (28.6)	18 (30.5)	.47
Male	6 (60)	35 (71.4)	41 (69.5)	
Age, median (IQR)	42 (9)	43.5 (16)	43 (13)	.71
32–39	1 (10)	14 (29.2)	15 (25.9)	.16
40–49	7 (70)	18 (37.5)	25 (43.1)	
50–66	2 (20)	16 (33.3)	18 (31.0)	
Number of IBD patients seen per week, <i>n</i> (%)				
1–10	1 (10)	13 (21.3)	14 (19.7)	.23
11–20	2 (20)	23 (37.7)	25 (35.2)	
>21	7 (70)	25 (41)	32 (45.1)	
Years of post-training, median (IQR)	10.5 (6)	10 (15)	10 (15)	.90
Rural/urban, <i>n</i> (%)				
Urban	9 (100)	44 (72.1)	53 (75.7)	.07
Rural	0 (0)	17 (27.9)	17 (24.3)	
Training in IBD beyond specialty program, <i>n</i> (%)				
IBD fellowship	3 (30)	10 (21.3)	13 (22.8)	.23
None	7 (70)	26 (55.3)	33 (57.9)	
Other	0 (0)	11 (23.4)	11 (19.3)	

Abbreviation: IBD, inflammatory bowel disease.

^aP value from chi-square test for categorical variables or *t*-test for continuous variables (if assumption of normality were not met, then Mann–Whitney tests were used; median and IQR were reported).

^bTotal varies for different variables for different number of missing values.

Statistical Analysis

Response rate was calculated by dividing the number of respondents by the estimated total number of luminal gastroenterologists in Canada to whom the survey was distributed. Characteristics of respondents were summarized using descriptive statistics. Continuous variables were reported as means and SDs, and categorical variables as counts and percentages. Group comparisons were performed between respondents affiliated with collaborative and non-collaborative IBD centers using chi-square test for categorical variables, and *t*-tests for continuous variables. If assumption of normality were not met, then Mann–Whitney tests were used and median and interquartile range reported. The level of significance was $P < .05$. Analyses were conducted using SAS 9.4 for Windows (SAS).

Ethical Considerations

The study was approved by the Nova Scotia Health Authority Research Ethics Board (File #1022789).

Results

Response Rate and Respondent Demographics

The individual clinician response rate was 10% (72 of 704). Of the respondents, 14% (10 of 72) were affiliated with collaborative IBD centers and 86% (62 of 72) were affiliated with non-collaborative IBD centers. Seven unique collaborative centers and 55 unique non-collaborative centers were identified. More than two-thirds of respondents were male

with a median age of 43 years. Respondents had been in clinical practice for a median of 10 years in a nonacademic setting. Less than one-quarter of respondents reported completing an IBD fellowship. The demographic characteristics of the respondents are summarized in [Table 1](#).

IBD Clinic Information

More than half of all respondents practiced in Ontario (34.7%) or Alberta (20.8%) ([Table 2](#)). Unique collaborative care center-affiliated respondents were in Alberta ($n = 2$), British Columbia ($n = 1$), Manitoba ($n = 1$), Nova Scotia ($n = 2$), and Quebec ($n = 1$). In comparison to non-collaborative care centers, all collaborative care centers had academic affiliations (100% vs 58.1%, $P = .01$). Most collaborative care centers were hospital-based (70% vs 20%) and non-collaborative centers were community based (41.7% vs 0%, $P = .006$). In addition, non-collaborative centers had significantly more solo practitioners compared with collaborative centers (51.6% vs 20%, $P = .01$).

Safety and Quality Improvement

Fewer than one-third of respondents indicated their center had a mechanism for recording adverse events related to IBD management and fewer than 10% of respondents indicated their center had a mechanism to monitor the implementation of a standardized clinical care pathway. Approximately 15% of respondents indicated their center measured QIs (with most using an electronic platform) and these were reportedly reviewed at least once per year. Most respondents

Table 2. IBD center information.

Parameter	Collaborative care	Non-collaborative care	Overall	<i>P</i> ^a
	<i>N</i> ^b = 10	<i>N</i> = 62	<i>N</i> = 72	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Province				
Alberta	2 (20)	13 (21)	15 (20.8)	.06
British Columbia	1 (10)	4 (6.5)	5 (6.9)	
Manitoba	1 (10)	3 (4.8)	4 (5.6)	
New Brunswick	0 (0)	2 (3.2)	2 (2.8)	
Newfoundland	0 (0)	4 (6.5)	4 (5.6)	
Nova Scotia	5 (50)	6 (9.7)	11 (15.3)	
Ontario	0 (0)	25 (40.3)	25 (34.7)	
Quebec	1 (10)	4 (6.5)	5 (6.9)	
Saskatchewan	0 (0)	1 (1.6)	1 (1.4)	
Academic affiliation				
No	0 (0)	26 (41.9)	26 (36.1)	.01
Yes	10 (100)	36 (58.1)	46 (63.9)	
Clinic type				
Academic	2 (20)	14 (23.3)	16 (22.9)	.006
Community based	0 (0)	25 (41.7)	25 (35.7)	
Hospital based	7 (70)	12 (20)	19 (27.1)	
Private	1 (10)	9 (15)	10 (14.3)	
Type of practice				
Group practice	6 (60)	29 (46.7)	35 (48.6)	.01
Other	2 (20)	1 (1.6)	3 (4.2)	
Solo practice	2 (20)	32 (51.6)	34 (47.2)	
Individuals involved in group practice				
Nurse practitioners	7 (70)	13 (31)	20 (38.5)	.02
Nurses	8 (80)	26 (61.9)	34 (65.4)	
Other gastroenterologists	8 (80)	31 (73.8)	39 (75)	
Other	3 (30)	14 (33.3)	17 (32.7)	

Bolded statistically significant results. Abbreviation: IBD, inflammatory bowel disease.
^a*P* value from chi-square test for categorical variables or *t*-test for continuous variables.
^bTotal varies for different variables for different number of missing values.

reported working in centers that implemented evidence-based or standardized clinical care pathways; however, only 3% of respondents stated their center performed audits of adherence to these standardized pathways. There were no statistically significant differences between collaborative and non-collaborative centers (Table 3).

Access to Care

Most centers (82%) had a triage process for IBD referrals and most indicated physicians reviewed the referrals (74%). More collaborative care centers reported recording patient wait times for new IBD referrals compared with non-collaborative care center (60% vs 26%, *P* = .03). There was no significant difference in perceived patient wait time or how referrals were assessed between collaborative care and non-collaborative care centers. There was a significant difference in how patients could access clinics. Compared with non-collaborative care centers, all collaborative care centers reported ways that patients could access the IBD clinic, including calling a gastroenterologist (100% vs 65.3%, *P* = .03) or IBD nurse (100% vs 46.2%, *P* = .001) (Table 4).

Patient Assessment and Referral Process

More than half of respondents indicated that patients see general gastroenterologists at clinic visits while less than 5% indicated patients see social workers or surgeons. There were no statistically significant differences between respondents affiliated with collaborative and non-collaborative care clinics. However, patients visiting collaborative care clinics for the first time were more likely to see gastroenterology subspecialists (80% vs 43.8%, *P* = .04), gastroenterology residents (70% vs 24.2%, *P* = .004) and/or research nurses (40% vs 3.2%, *P* < .0001) compared with those visiting non-collaborative care clinics for the first time (Table 5).

Patient Education and Empowerment

Approximately one-third of respondents indicated their center updated informational or educational material for patients on a regular basis, with two-thirds citing changes made to patient information sheets every 1 or more years. More than 85% of respondents worked in centers where patients receive resources about IBD and IBD-related medications while fewer than 50% worked in centers where patients receive resources

Table 3. Safety and quality^c improvement.

Parameter	Collaborative care	Non-collaborative care	Overall	P
	N ^b = 10	N = 62	N = 72	
	n (%)	n (%)	n (%)	
<i>Adverse event recording</i>				
No	6 (60)	27 (49.1)	33 (50.8)	.26
Uncertain	3 (30)	9 (16.4)	12 (18.5)	
Yes	1 (10)	19 (34.6)	20 (30.8)	
<i>Standardized clinical care pathway</i>				
No	9 (90)	42 (77.8)	51 (79.7)	.35
Uncertain	1 (10)	3 (5.6)	4 (6.3)	
Yes	0 (0)	9 (16.7)	9 (14.1)	
<i>Clinical care pathway implementation monitoring</i>				
No	9 (90)	41 (75.9)	50 (78.1)	.53
Uncertain	1 (10)	8 (14.8)	9 (14.1)	
Yes	0 (0)	5 (9.3)	5 (7.8)	
<i>Quality indicator measuring</i>				
No	4 (40)	35 (68.6)	39 (63.9)	.20
Uncertain	4 (40)	9 (17.7)	13 (21.3)	
Yes	2 (20)	7 (13.7)	9 (14.8)	
If yes				
Recorded using a paper-based system				
No	1 (50)	3 (60)	4 (57.1)	.81
Yes	1 (50)	2 (40)	3 (42.9)	
Recorded using an electronic system (ie, electronic medical record)				
No	0 (0)	2 (33.3)	2 (25)	.35
Yes	2 (100)	4 (66.7)	6 (75)	
Reviewed at least once per year				
No	1 (50)	1 (20)	2 (28.6)	.43
Yes	1 (50)	4 (80)	5 (71.4)	
Used to provide feedback to practitioners				
No	2 (100)	3 (50)	5 (62.5)	.21
Yes	0 (0)	3 (50)	3 (37.5)	
<i>Implementation of evidence-based or standardized clinical care pathways</i>				
Immunosuppressive therapy				
No	3 (33.3)	13 (24.5)	16 (25.8)	.58
Yes	6 (66.7)	40 (75.5)	46 (74.2)	
Biologic therapy				
No	3 (30)	11 (20.8)	14 (22.2)	.52
Yes	7 (70)	42 (79.2)	49 (77.8)	
Investigations				
No	4 (40)	18 (34.0)	22 (34.9)	.71
Yes	6 (60)	35 (66.0)	41 (65.1)	
Follow-up intervals				
No	5 (50)	30 (56.6)	35 (55.6)	.70
Yes	5 (50)	23 (43.4)	28 (44.4)	
Monitoring disease activity				
No	3 (30)	17 (32.7)	20 (32.3)	.87
Yes	7 (70)	35 (67.3)	42 (67.7)	
Monitoring disease associated adverse events				
No	7 (70)	30 (56.6)	37 (58.7)	.43
Yes	3 (30)	23 (43.4)	26 (41.3)	

Table 3. Continued

Parameter	Collaborative care	Non-collaborative care	Overall	P
	N ^b = 10	N = 62	N = 72	
	n (%)	n (%)	n (%)	
Surveillance colonoscopy				
No	3 (30)	19 (36.5)	22 (35.5)	.69
Yes	7 (70)	33 (63.5)	40 (64.5)	
IBD care during pregnancy				
No	3 (33.33)	24 (46.2)	27 (44.3)	.47
Yes	6 (66.67)	28 (53.8)	34 (55.7)	
Monitoring audits of adherence to clinical care pathways				
No	7 (70)	45 (86.5)	52 (83.9)	.19
Uncertain	3 (30)	5 (9.6)	8 (12.9)	
Yes	0 (0)	2 (3.9)	2 (3.23)	
Assessment of patient wellbeing				
Patient satisfaction				
No	6 (60)	32 (61.5)	38 (61.3)	.93
Yes	4 (40)	20 (38.5)	24 (38.7)	
Disease-related psychosocial distress				
No	6 (60)	32 (64)	38 (63.3)	.81
Yes	4 (40)	18 (36)	22 (36.7)	
Day missed from school or work				
No	7 (70)	35 (68.6)	42 (68.9)	.93
Yes	3 (30)	16 (31.4)	19 (31.1)	
Patient quality of life				
No	4 (44.4)	26 (50)	30 (49.2)	.76
Yes	5 (55.6)	26 (50)	31 (50.8)	
Nutritional status				
No	4 (44.4)	22 (44)	26 (44.1)	.98
Yes	5 (55.6)	28 (56)	33 (55.9)	

Abbreviations: EPIC, Emerging Practice in IBD Collaborative; IBD, inflammatory bowel disease; PACE, Promoting Access and Care Through Centres of Excellence.

^aP value from chi-square test for categorical variables or *t*-test for continuous variables.

^bTotal varies for different variables for different number of missing values.

^cQuality indicators including standardized clinical care pathway metrics were derived from the measures outlined in the PACE and EPIC guidelines.^{4,5} Please reference these guidelines for the parameters.

about surgical interventions, nutrition, or patient support groups. Fewer than 15% of respondents indicated patients receive a management summary after each clinic visit. There was a statistically significant difference in how collaborative and non-collaborative care centers collected patient feedback, with more collaborative centers using patient surveys (100% vs 21.4%, *P* = .002) and focus groups (25% vs 0%, *P* = .007) (Table 6).

Discussion

Clinical standards and expectations of models of IBD care are changing. There has been a global shift toward collaborative care models to improve access to holistic patient care, assessment, and education.⁷ Multiple studies have demonstrated improved patient outcomes when multidisciplinary care is implemented.¹⁰⁻¹⁷ However, little is known about the current reality of IBD care models in Canada. Existing research on QIs in Canada has largely focused on transitional care between pediatric and adult centers,^{23,24} or on consensus building and clinical guidelines.^{4,5,25} This study was the first national survey

attempting to describe the structure and process characteristics of IBD care models in Canada. We recognize our findings are derived from a small sample size and may not be representative of all models of IBD care in Canada. Nevertheless, our findings are provided within this context to provide some initial information about the landscape of IBD care in Canada.

Most respondents were affiliated with non-collaborative care centers which had an approximate 60/40 split between academic and nonacademic programs, while all respondents working in collaborative care centers were affiliated with an academic institution. This distribution is not surprising given that academic centers are typically located in urban areas and may have improved access to multidisciplinary teams and greater human and financial resources. Further, many gastroenterologists working in nonacademic centers have solo, busy, fee-for-service practices which may act as a barrier to implementing a collaborative model. Although the response rate was low, presumably those most motivated to respond did and response rates from 62 unique centers across 9 provinces were obtained. Of those respondents, 10 practiced at 7 unique collaborative centers distributed across 5 provinces.

Table 4. Patient access to IBD care centers.

	Collaborative care N ^b = 10	Non-collaborative care N = 62	Overall N = 72	P
Availability of triage process for IBD referrals, <i>n</i> (%)				
No	1 (10)	10 (19.6)	11 (18)	.47
Yes	9 (90)	41 (80.4)	50 (82)	
Staff who reviews IBD referrals, <i>n</i> (%)				
Nurse	1 (11.1)	6 (14.6)	7 (14)	.57
Physician	6 (66.7)	31 (75.6)	37 (74)	
Physician administrator	0 (0)	1 (2.4)	1 (2)	
Physician nurse	2 (22.2)	3 (7.3)	5 (10)	
Method of notifying patients of their clinic appointment? <i>n</i> (%)				
By email	0 (0)	3 (5.8)	3 (4.9)	.22
By mail	5 (50)	11 (21.6)	16 (26.2)	
By phone	5 (50)	32 (62.7)	37 (60.6)	
Other	0 (0)	5 (9.8)	5 (8.2)	
Recording patient wait times for new IBD referrals, <i>n</i> (%)				
No	3 (30)	36 (72)	39 (65)	.03
Uncertain	1 (10)	1 (2)	2 (3.3)	
Yes	6 (60)	13 (26)	19 (31.7)	
Average number of weeks before a new IBD patient is seen in clinic when triaged as urgent, <i>n</i> (%)				
1–2 weeks	6 (60)	31 (60.8)	37 (60.7)	.85
3–4 weeks	2 (20)	12 (23.5)	14 (23)	
5–6 weeks	2 (20)	5 (9.8)	7 (11.5)	
7–8 weeks	0 (0)	2 (3.9)	2 (3.3)	
9–12 weeks	0 (0)	1 (2)	1 (1.6)	
Average number of weeks on before a new IBD patient is seen in clinic when triaged as non-urgent, <i>n</i> (%)				
13–17 weeks	2 (20)	2 (4.1)	4 (6.8)	.09
18+ weeks	3 (30)	6 (12.2)	9 (15.3)	
3–4 weeks	0 (0)	12 (24.5)	12 (20.3)	
5–6 weeks	1 (10)	9 (18.4)	10 (17)	
7–8 weeks	0 (0)	7 (14.3)	7 (11.9)	
9–12 weeks	4 (40)	13 (26.5)	17 (28.8)	
Clinic hours of operation, <i>n</i> (%)				
Regular work hour	10 (100)	52 (100)	62 (100)	.08
Extended hour weekday	0 (0)	4 (7.7)	4 (6.5)	.36
Weekends	0 (0)	5 (9.6)	5 (8.1)	.31
Health care providers who refer patients, <i>n</i> (%)				
Gastroenterologist	10 (100)	42 (80.8)	52 (83.9)	.13
General internists	9 (90)	47 (90.4)	56 (90.3)	.97
Internal medicine subspecialty	9 (90)	45 (86.5)	54 (87.1)	.76
General surgeons	9 (90)	47 (90.4)	56 (90.3)	.97
Family physicians	9 (90)	50 (96.2)	59 (95.7)	.41
Nurse practitioners	8 (80)	34 (65.4)	42 (67.7)	.37
Patients	0 (0)	1 (1.9)	1 (1.6)	.66
Other	0 (0)	2 (3.9)	2 (3.2)	.53
Information used to prioritize referrals? <i>n</i> (%)				
Disease relative complexity	10 (100)	38 (73.1)	48 (77.4)	.06
Disease phenotype	6 (60)	21 (40.4)	27 (43.6)	.25
Disease activity	8 (80)	39 (75)	47 (75.8)	.74
Inflammation biomarkers	9 (90)	38 (73.1)	47 (75.8)	.25
Albumin	5 (50)	23 (44.2)	28 (45.2)	.74
Patient age	1 (10)	17 (32.7)	18 (29)	.15

Table 4. Continued

	Collaborative care N ^b = 10	Non-collaborative care N = 62	Overall N = 72	P
Patient symptoms	10 (100)	49 (94.2)	59 (95.2)	.44
Hemoglobin	8 (80)	30 (57.7)	38 (61.3)	.18
Cross-sectional imaging	7 (70)	23 (44.2)	30 (48.4)	.14
White blood cell count	3 (30)	10 (19.2)	13 (21)	.44
Other	1 (10)	3 (5.8)	4 (6.45)	.62
Occurrence of Patient Appointment Events, <i>n</i> (%)				
Patient receives reminder prior to appointment	8 (80)	37 (71.2)	45 (72.6)	.57
Scheduled vs actual start time of clinic visit recorded	1 (10)	11 (21.2)	12 (19.4)	.41
No show/cancellation rate monitored	4 (40)	26 (50)	30 (48.4)	.56
Other	1 (10)	1 (1.9)	2 (3.2)	.19
Referring physician notified about missed appointment	6 (60)	35 (67.3)	41 (66.1)	.65
Nothing	1 (10)	2 (3.9)	3 (4.8)	.41
How patients access IBD clinic, <i>n</i> (%)				
Call GI	10 (100)	34 (65.4)	44 (71)	.03
Call IBD Nurse	10 (100)	24 (46.2)	34 (54.8)	.001
Call Administrative Assistant	9 (90)	32 (61.5)	41 (66.1)	.08

Bolded statistically significant results. Abbreviation: IBD, inflammatory bowel disease.
^aP value from chi-square test for categorical variables or *t*-test for continuous variables.
^bTotal varies for different variables for different number of missing values.

Given the low response rate, it is possible that other collaborative and non-collaborative centers exist. For example, only 1 collaborative center in Ontario and Quebec were reported despite these being Canada’s largest provinces. More responses were received from Nova Scotia which may be due to the survey originating from this province. These results generally suggest that fewer true collaborative care centers exist across Canada in comparison to non-collaborative care centers. Based on global evidence, increasing the availability of collaborative centers may improve the quality of IBD care and patients’ quality of life, while aligning Canada with evolving global clinical standards.

There was a somewhat discordant observation of a lack of significant differences between implemented QIs in collaborative and non-collaborative care centers. This may be due in part to a small sample size, which would limit the power to detect significant differences, or response bias on the part of participants who perceived implementation of QIs despite a lack of actual implementation. Nevertheless, our data suggest that there are clear areas for quality improvement. There was a significant difference between some indicators of access, including the recording of wait times and how patients could communicate with the clinic. Limited communication with the IBD specialist and lack of wait time updates have previously been identified as barriers to quality care.²⁶ Secondly, less than half of IBD centers provided formal patient education. Gastroenterologists may assume patients receive this information through other resources (online, etc.) or they may not have easy access to this information while in clinic. Time limitations and lack of multidisciplinary human resources may also play a role.²⁷ Furthermore, very few centers monitored adverse events related to IBD management or measured QIs. This information is critical for patient safety but can be difficult to obtain depending on how medical information

is collected and stored. Ideally, this information would be stored in an updated database and reviewed frequently so that any changes affecting patient care could be made in a timely manner. However, there is often significant heterogeneity between data systems within hospitals and across geographic jurisdictions. This poses logistical challenges for creating and maintaining a database that is accurate, reflective of practice and usable for quality improvement efforts. Although most respondents indicated that their centers implement standardized clinical care pathways in some form, only 3% reported conducting regular audits of adherence to these pathways. Therefore, it is difficult to know how often physicians implement formal care pathways in real-world practice versus perceiving they are implementing them.

These data are the first step to describing the real-world uptake of clinical care and quality improvement guidelines in Canada. It provides a starting point by identifying potential care gaps in clinical care delivery for IBD, and may inform the development of targeted interventions to address such gaps and improve patient care, such as electronic medical record-based templates for implementation and evaluation of evidence-based care in clinical practice. For example, a standard 10-minute clinic consultation is inadequate to perform comprehensive clinical assessments and monitor all relevant patient outcomes, safety, and QIs. Some patients may make multiple consultation appointments or visits to the emergency department if they have health concerns. These visits result in high financial and human resource consumption, which is costly to the health care system. A phone app was developed in partnership with clinicians and patient groups in the Netherlands where patients could record disease-related concerns and communicate with clinicians. Patients and clinicians indicated high satisfaction and, as a result, there was a reduction in hospital admissions by

Table 5. Patient assessment and referral process in IBD care centers.

Parameter	Collaborative care N ^b = 10	Non-collaborative care N = 62	Overall N = 72	P ^a
Referral to other specialist made after, <i>n</i> (%)				
Assessment by IBD nurse alone	0 (0)	1 (2)	1 (1.7)	.002
Assessment by IBD nurse and physician	2 (20)	6 (12)	8 (13.3)	
Assessment by multidisciplinary team	1 (10)	0 (0)	1 (1.7)	
Assessment by physician alone	5 (50)	43 (86)	48 (80)	
Other	2 (20)	0 (0)	2 (3.3)	
Specialist referral process, <i>n</i> (%)				
Emailing the referral	0 (0)	1 (2)	1 (1.7)	.88
Faxing a paper copy of the referral	7 (70)	30 (60)	37 (61.7)	
Speaking directly with the specialist	1 (10)	9 (18)	10 (16.7)	
Health care professional consultations at first appointment, <i>n</i> (%)				
Administrator	1 (10)	8 (16.7)	9 (15.5)	.60
General Gastroenterologist	4 (40)	28 (58.3)	32 (55.2)	.29
Nurse	6 (60)	15 (31.3)	21 (36.2)	.09
Medical student	2 (20)	13 (27.1)	15 (25.9)	.64
Medical resident	6 (60)	15 (31.3)	21 (36.2)	.09
Surgical resident	0 (0)	2 (4.2)	2 (3.4)	.51
Dietician	1 (10)	2 (4.2)	3 (5.2)	.45
Social worker	0 (0)	1 (2.1)	1 (1.7)	.65
General Practitioner	0 (0)	1 (2.1)	1 (1.7)	.65
Other	1 (10)	2 (4.2)	3 (5.2)	.45
Research Nurse	4 (40)	2 (3.2)	6 (8.3)	<.0001
GI resident	7 (70)	15 (24.2)	22 (30.6)	.004
Specialty Gastroenterologist	8 (80)	21 (43.8)	29 (50)	.04
Health care professional consultations at follow-up appointment, <i>n</i> (%)				
Administrator	1 (10)	6 (12.5)	7 (12.1)	.83
General Gastroenterologist	5 (50)	28 (58.3)	33 (56.9)	.63
Specialty Gastroenterologist	8 (80)	23 (47.9)	31 (53.4)	.06
Nurses	6 (60)	19 (39.6)	25 (43.1)	.24
Medical student	4 (40)	14 (29.2)	18 (31)	.50
Medical resident	5 (50)	15 (31.3)	20 (34.5)	.26
Surgical resident	0 (0)	3 (6.3)	3 (5.2)	.42
Dieticians	0 (0)	3 (6.3)	3 (5.2)	.42
Social worker	0 (0)	2 (4.2)	2 (3.4)	.51
General Practitioner	0 (0)	1 (2.1)	1 (1.7)	.65
Other	2 (20)	3 (6.3)	5 (8.6)	.16
Research nurse	4 (40)	2 (3.2)	6 (8.3)	<.0001
GI residents	6 (60)	14 (22.6)	20 (27.8)	.01

Bolded statistically significant results. Abbreviation: IBD, inflammatory bowel disease.

^aP value from chi-square test for categorical variables or *t*-test for continuous variables.

^bTotal varies for different variables for different number of missing values.

50% and outpatient clinic visits by 37% without compromising safety and quality of care.²⁸ Whether the resources exist within the Canadian health care system to accommodate intensive monitoring of this type of app is not clear. However, the development and design of additional innovative strategies for improving access to high-quality disease monitoring and care should be developed.

Perhaps most importantly, these data underscore the gap between what experts and academics recommend as best practice for IBD care and the reality of limited resources for

implementing these recommendations. In the current resource constrained Canadian health care environment, more than ever, decisions regarding allocation of clinical resources and how they are best delivered must be informed by data derived from the study of real-world implementation and effectiveness of care delivery models. Our findings are especially relevant given clinical access concerns and more stringent resource allocation during the COVID-19 pandemic and in a postpandemic health care system.²⁹ This study serves as an important snapshot of the current state of IBD care delivery

Table 6. Patient empowerment and education initiatives.

Parameter	Collaborative care N ^b = 10	Non-collaborative care N = 62	Overall N = 72	P ^a
Material regularly updated, <i>n</i> (%)				
No	3 (30)	27 (55.1)	30 (50.8)	.35
Uncertain	2 (20)	6 (12.2)	8 (13.6)	
Yes	5 (50)	16 (32.7)	21 (35.6)	
Frequency of changes made to patient information sheets? <i>n</i> (%)				
Every 13–18 months	2 (22.2)	4 (9.5)	6 (11.8)	.46
Every 18–24 months	2 (22.2)	5 (11.9)	7 (13.7)	
Every 24+ months	4 (44.4)	17 (40.5)	21 (41.2)	
Every 6 months or less	0 (0)	8 (19)	8 (15.7)	
Every 7–12 months	1 (11.1)	8 (19)	9 (17.6)	
Changes made based on patient feedback alone, <i>n</i> (%)				
No	4 (40)	20 (43.5)	24 (42.9)	.92
Uncertain	3 (30)	15 (32.6)	18 (32.1)	
Yes	3 (30)	11 (23.9)	14 (25)	
Resources available at care center, <i>n</i> (%)				
IBD resources	10 (100)	43 (82.7)	53 (85.5)	.15
Medication resources	10 (100)	44 (84.6)	54 (87.1)	.18
Surgical intervention resources	5 (50)	12 (23.1)	17 (27.4)	.08
Nutritional resources	6 (60)	20 (38.5)	26 (41.9)	.21
Advocacy group information	7 (70)	23 (44.2)	30 (48.4)	.14
Support program information	5 (50)	24 (46.2)	29 (46.8)	.82
Summary of disease management after clinic	1 (10)	8 (15.4)	9 (14.5)	.66
Method of gathering patient feedback, <i>n</i> (%)				
Patient satisfaction survey	4 (100)	6 (21.4)	10 (31.3)	.002
Focus groups	1 (25)	0 (0)	1 (3.1)	.007
Invited comments	1 (25)	16 (57.1)	17 (53.1)	.23
Material provided to referring physicians and/or family physicians, <i>n</i> (%)				
Letters from clinics	9 (90)	46 (95.8)	55 (94.8)	.45
Relevant investigations	7 (70)	33 (68.8)	40 (69)	.94
Diagnostic reports	7 (70)	34 (70.8)	41 (70.7)	.96
Management plans	5 (50)	31 (64.6)	36 (62.1)	.39
Questionnaires about the quality of communication from the clinic	0 (0)	1 (2.1)	1 (1.7)	.65
No direct communication between clinic and referring physician	0 (0)	1 (2.1)	1 (1.7)	.65

Bolded statistically significant results. Abbreviation: IBD, inflammatory bowel disease.

^aP value from chi-square test for categorical variables or *t*-test for continuous variables.

^bTotal varies for different variables for different number of missing values.

in Canada and provides a “jumping off point” for future research and quality improvement initiatives.

Limitations

The overall response rate to our survey was low despite employing multiple strategies to maximize responses. This may be related to the volume of surveys received by physicians, the time associated with completing the survey or the method of broadcasting the survey. The issue of low to very low response rates of physicians in surveys has been recognized in the literature as a key challenge in health care research.³⁰ The low sample size is a major limitation of the paper, as some information about IBD care centers in Canada may not have been reported. There are also limitations to using cross-sectional studies, such as participation bias and

recall bias related to physician self-reporting. We have tried to limit bias by recruiting through many channels and providing sociodemographic information to characterize those who responded.

Conclusions

This study is the first national study to characterize the structure and processes of IBD collaborative care models in Canada. Within the context of a small sample size, our findings suggest that few IBD collaborative centers currently exist in Canada, and more should be made available to align with international standards. We also identified areas for improvement in existing care centers, including the recording of patient wait time and patient education information. Focusing

on these elements may improve the quality of IBD care in existing care centers and patients' quality of life. Given the resource constraints within the Canadian health care system, attention should be focused on the development and design of innovative strategies that support the implementation of QIs in IBD care centers.

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Authors' Contributions

M.M., J.N.P.-S., C.H., M.S., and J.L.J.: study design, data collection, report writing, and project oversight. Y.C.: study design, data analyses, and report writing. H.M.: study design and report writing.

Conflicts of Interest

None declared.

Data Availability

Data not publicly available.

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