



Alimentary Tract

Harmonization of quality of care in an IBD center impacts disease outcomes: Importance of structure, process indicators and rapid access clinic

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ABSTRACT

Background and aims: We aimed to evaluate the quality of care at a tertiary inflammatory bowel disease (IBD) center using quality of care indicators (QIs) including patient assessment strategy, monitoring, treatment decisions and outcomes.

Methods: We retrospectively reviewed the quality of care pre- and post-referral and during follow-up at the McGill University Health Center (MUHC) IBD center. Consecutive patients were included presenting with an outpatient visit ('index visit') between July and December 2016. Disease characteristics, biochemistry, imaging and endoscopy data, changes in medications, and vaccination profiles were captured.

Results: 1357 patients were included. At referral, a large proportion of patients were objectively re-evaluated (ileocolonoscopy: 79%, cross-sectional imaging: 39.3%, biomarkers: 89.9%, 81.9%). Therapeutic strategy was changed in 53.6% with 22.5% of patients starting biologics. Tight objective patient monitoring was applied during follow-up (colonoscopy: 79%, cross-sectional imaging: 61.8% were available at index visit; C-reactive protein: 78%, Faecal calprotectin: 37.6%, therapeutic drug monitoring: 16.3% were performed additionally). Maximum therapeutic step was biologics in 48.8% of the patients, while only 6.6% of all patients were steroid dependent. Implementation of a rapid access clinic improved healthcare delivery.

Conclusions: Our data support that tight monitoring was applied at the MUHC IBD center with a high emphasis on objective patient (re)evaluation, timely access and accelerated treatment strategy at referral and during follow-up.

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1. Introduction

Inflammatory bowel diseases (IBD) are chronic progressive and disabling conditions affecting mainly young adults. IBD impacts substantially on the patient's physical health, social functioning and quality of life contributing to the high health-economic burden associated to the disease [1–3]. With the advent of biological

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therapies, the management of patients with IBD has changed significantly in the last decade.

Recent advancements have been catalyzed by evidence suggesting that targeting symptom-based outcome parameters does not largely alter the natural course of IBD [4,5]. Inspired by evidence in other specialties, notably from the rheumatoid arthritis literature, the International Organization for the Study of Inflammatory Bowel Diseases (IOIBD) devised the STRIDE recommendations with the objective of providing a treat-to-target framework for IBD [6]. In parallel, ongoing evidence was mounting in the IBD literature regarding the association of endoscopic healing with improved clinical and long-term outcomes. This supports the notion of treating-to-target in IBD patients [7]. The STRIDE recommenda-

tions include targeting improvement in clinical and endoscopic outcomes and also incorporate patient reported outcome measures (PRO). These recommendations give rise to the potential of a greater impact on IBD compared to the former symptom derived scales including the Crohn's Disease Activity Index (CDAI) or the partial Mayo Score. Virtually all newly designed and recently published clinical trials in IBD have moved toward a similar structure focusing on complex outcomes encompassing clinical, endoscopic and PRO improvements [8].

A major challenge in the field of IBD lies in the large heterogeneity in clinical practice. This variation in everyday practice is seen in many domains of IBD management such as diagnostic testing, disease activity monitoring, therapeutic interventions and knowledge of preventative care recommendations [9–11]. As a result of the apparent differences in practice, a major interest was sparked in devising a standard set of measures to evaluate quality of care (QoC). This occurred by developing quality indicators (QIs). QIs may be related to three components in health care: structure, process and outcome parameters of care [12,13]. The goal is to uncover a set of QIs which could be used worldwide in IBD or gastroenterology units for comparison to harmonize and augment the level of care delivered to patients with IBD. Comprehensive evaluation of quality of care provided by IBD centers or country profiles based on the above measures is still scarce. Notably, Gonczi et al. reported good results on their center's performance using well established structure, function and outcome QIs [14]. Most recent publications highlight significant gaps and need for improvement in the quality of care of IBD [15–17].

We aimed to evaluate the quality of care at a formal tertiary IBD center in Canada using quality of care indicators (QIs) including patient assessment strategies, disease monitoring, treatment decisions and health-related outcomes as suggested by the PACE [18] (Promoting Access and Care through Centres of Excellence) and STRIDE [6] recommendations; and the impact of implementing a rapid access clinic (RAC) for improving healthcare services in IBD.

2. Methods

2.1. Structure of the McGill University Health Centre's (MUHC) IBD center

The MUHC IBD center was officially established in July 2016 and is one of the first formal IBD centers in Canada which houses a team of medical professionals skilled in various areas related to the management of patients with IBD (see Table 1). The structure of the MUHC IBD center was based on the PACE program developed by the Crohn's and Colitis Canada organization. The goal of a PACE site is

to offer complete multi-faceted care to the IBD patient at one site as well as provide leadership, research, and training for IBD care.

An important structural component of the MUHC IBD center is the rapid access clinic (RAC), which provides IBD patients an opportunity to be evaluated by IBD specialists urgently without having to present to the Emergency Department. The RAC was structured by providing IBD patients followed at the MUHC IBD center with an emergency contact email address, with a specific document explaining the pertinent symptoms that merit utilization of this access avenue. Each email was read and reviewed by a specialized IBD nurse or physician and depending on the situation a RAC visit was booked.

2.2. Retrospective substudy

The first part of this study was a retrospective analysis of the quality of care IBD patients were receiving before and after their referral to an MUHC IBD specialist ('referral visit') and up until their first visit at the newly established MUHC IBD Center ('index visit'). Consecutive patients were included with an outpatient visit (index visit) at the MUHC IBD Center from July 2016 to December 2016. Demographic variables, outpatient visits, inpatient stays including IBD related surgery, laboratory, imaging and endoscopy data, current medications and/or changes in medications, and vaccination profiles were captured. Prior to the patient's referral to an MUHC IBD specialist, the diagnostic workup, treatment strategy and outcomes were obtained. Once the patient was evaluated by the MUHC IBD specialist, the details of re-assessment including disease evaluation, additional diagnostic workup, and changes in treatment strategy were obtained. Patient monitoring, treatment strategy and outcomes were collected at the index visit (including data on patient follow-up within 2 years prior the index visit and for 6 months thereafter), evaluating the quality of care during follow-up at the newly established MUHC IBD center. (see Fig. 1).

The evaluation of the quality of care of IBD patients was based on the presence of a selected set of quality indicators (QI) in the patient charts (see Table A1 – online presentation). The chosen QIs were established by the PACE program in order to improve IBD patient outcomes and address gaps in care of patients with IBD.

2.3. Prospective substudy: rapid access clinic (RAC)

Data from the newly started RAC regarding patient access, resource utilization and outcomes were obtained between July 2017 to July 2018. The following data was captured: validity of request, access: Time from email to RAC visit, patient management (utilization of biomarkers, TDM, endoscopy, imaging, request of ER visit/admission/surgery), frequency of treatment strategy changes, outcomes (frequency of unplanned ER visits/admission within 30 and 90 days from RAC visit).

2.4. Statistical analysis

Anonymized data were collected and stored in Excel in a password protected document. The statistical analysis included descriptive statistics of demographic variables, outcome and QI parameters, Chi2 and time adjusted (partial) COX models. Statistical analysis was performed by IBM SPSS 20.0 software. A p value of <0.05 was regarded as statistically significant.

2.5. Ethical consideration

The study protocol was approved by the MUHC Research Ethics Board. REB approval was obtained for the retrospective study. Writ-

Table 1
Layout of MUHC IBD centre.

Hospital characteristics
<ul style="list-style-type: none"> • Dedicated outpatient clinic • Endoscopy unit • Emergency department
Personnel and referral professionals
<ul style="list-style-type: none"> • 6 IBD specialist gastroenterologists • 2 IBD nurses • 2 research nurses • 2 IBD Fellows • Consultant expert colorectal surgeons and GI histopathologists • Affiliated dedicated radiologist • Access to dermatologist, rheumatologist, ophthalmologist • Stoma therapist

MUHC, McGill University Health Centre; IBD, inflammatory bowel disease; GI, gastrointestinal.

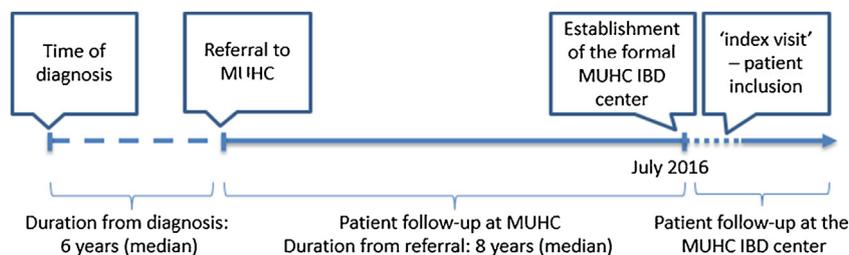


Fig. 1. Retrospective analysis of quality of care at referral and index visit.

Table 2
Demographics and clinical characteristics at referral.

1357 IBD patients	CD (n = 874)	UC (n = 483)
Age at onset (year, mean (SD))	27.7 (13.8)	33.5 (14)
Age at referral (year, mean (SD))	36.5 (15.3)	40.3 (15.4)
Age at index (year, mean (SD))	43.2 (16)	
Gender (male/female) %	47.5/52.5	45.5/54.5
^a Age group (A1/A2/A3) %	21.9/59.5/18.5	
^a Localization in CD (L1/2/3/4) %	29.9/20.5/49.5/5.9	
^a Behavior in CD (B 1/2/3) %	55/25.8/19.2	
Perianal disease in CD %	23.7	
^a Extension in UC (E 1/2/3) %		15.3/37.5/47.2
^a Severity in UC (S 1/2/3) %		58.3/27/14.7
Resectiver surgery %	25.2	
Colectomy %	4	4
Ostomy %	4.5	1
Extraintestinal manifestation %	35.5	21

IBD, inflammatory bowel disease; CD, Crohn's disease, UC, ulcerative colitis.

^a Based on the Montreal classification of IBD.

ten informed consent was obtained from patients included in the prospective study.

3. Results

3.1. Retrospective analysis

1357 patients (46.8% male, 64.4% Crohn's disease (CD), age at diagnosis: 29.8 years, age at referral: 39.3 years, duration of disease: 14.1 years) were included (see Table 2). At referral, 49.5% of CD patients had ileocolonic disease, 45% of these patients had complicated disease behaviors (stricturing or penetrating phenotypes) and 23.7% had perianal disease. 47.2% and 41.7% of UC patients were classified as having extensive and moderate- to severe disease, respectively.

3.1.1. Patient assessment and change of treatment strategy at referral to IBD center

Data regarding the evaluation of disease characteristics before referral to the MUHC IBD center was collected.

67.7% of patients had a documented previous ileocolonoscopy at referral and 35% patients had radiographic imaging performed (8.3% MRI and 26.7% CT). Sixty-five percent of CD and 45.5% of UC patients had at least mild disease activity at around referral. Moderate to severe activity was recorded in 28% of CD patients and 7.1% of UC patients, as defined by an HBI >8 or Mayo score >7, respectively. 54.7% of patients had presented to the emergency department (ER) for IBD related disease activity and 42.8% required hospitalization. 25.2% of CD patients had IBD-related surgery at some point during their disease course before referral. A minority of patients were treated with biologic therapy (14%). 71.7% of patients were employed.

On average, 6 years elapsed following an initial diagnosis of IBD until the patient was referred out to the MUHC IBD clinic/specialists. At referral a large proportion of patients were

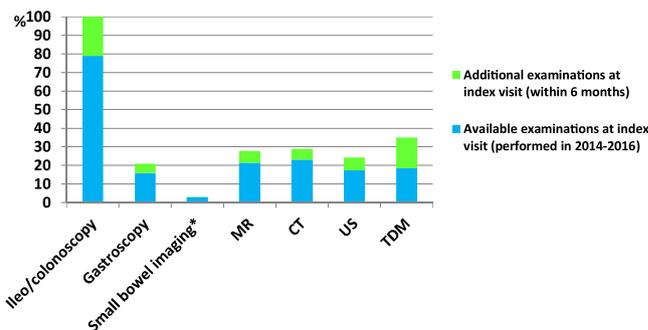


Fig. 2. Patient monitoring by endoscopy or cross-sectional imaging during follow-up.

objectively re-evaluated: 79% underwent ileocolonoscopy, 15.7% upper GI endoscopy, 15.6% of CD patients had abdomino-pelvic MRI or CT and 23.6% abdominal US. CBC, CRP and FCAL were measured in 89.9%, 81.9% and 16.5%, respectively. Medical therapy was changed in 53.6% (active disease: 75.6%, remission: 24.4%, $P < 0.001$), while 22.5% of patients started biological therapy at referral. 12.4% of patients required hospitalization while 6% required surgery at around referral (within 3–6 months from referral visit).

3.1.2. Patient monitoring and change of therapeutic strategy during follow-up at the MUHC IBD center

At the index visit (between July and December 2016), the patient population with respect to the extent of disease and phenotype was similar to that around the referral. However, after referral an additional 26.8% and 6.6% of CD and UC patients required resective surgeries for their disease, respectively.

Objective patient re-evaluation was common during regular follow-up: ileocolonoscopy or colonoscopy was performed in 68% and 11% within the last 2 years before the index visit, with an additional 26.8% and 5.2% within 6 months after the index visit. Imaging was available in an additional 21.4%, 23.2% and 17.3% of IBD patients using MRI, CT and US evaluation over the past 2 years before the index visit, respectively. Additional imaging to evaluate disease activity was ordered at the index visit included MRI (6.3%), CT (5.7%) and US (7%). The frequency of therapeutic drug monitoring (TDM) was escalated following the establishment of the IBD center. In 6 months, 16.3% of IBD patients had undergone TDM as compared to 18.5% over the past 2 years. Biomarkers were measured frequently at index visit (CRP: 78%, FCAL: 37.6%). Similarly, biologic and infectious workups were measured relatively more often: HBV/HCV and clostridium difficile testing was performed in 17.5% and 18% over 6 months, with an additional 45.2% and 35.9% patients having a test results within 2 years before index visit. (see Figs. 2 and 3).

At the index visit, 48.8% of patients were on biological therapy and 15.1% of patients were receiving steroids, while only 6.6% steroid dependent (see Fig. 4). Of note, 4.4% of patients were using narcotics (use of marijuana could not be estimated reliably). Active

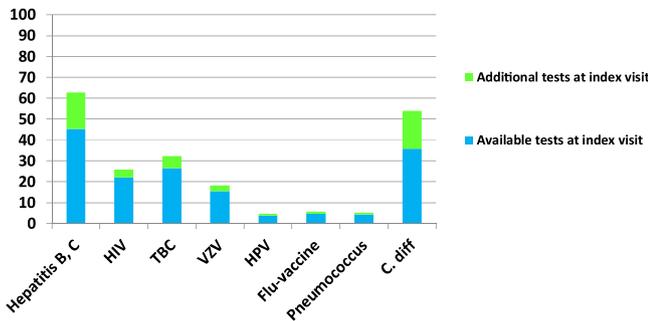


Fig. 3. Vaccination and infection screening profile during follow-up.

disease was identified in 59.1% of patients following their index visit. Treatment was changed in 17.8% of patients (active disease: 40.3%, patients in remission: 7.2%, $P < 0.01$). The need for surgery (4.3%) and hospitalization (7.6%) were relatively low, while 16.8% of patients needed an IBD-related ER visit within 6 months after index visit. Employment rates were high at 76.5%. Tight follow-up and monitoring was applied in the whole cohort, CD patients with active disease had more imaging procedures and biochemical tests than CD patients in remission (see Table A2 – online presentation).

3.2. Importance of a rapid access clinic (RAC) and its impact on ER utilization

261 consecutive patients (44.1% men, mean age: 39 years, CD: 64% [L3: 46.2%, B2–3: 31.8%], UC: 32% [extensive colitis: 56.6%], biological therapy: 61.6%, previous surgery: 20.4%) were included in this prospective substudy between June 2017 to July 2018. The RAC physician initially screened patient requests for urgent assessment. 85.7% ($n = 224$) of the requests were deemed appropriate for a rapid appointment. The median time to RAC visit was 3 days (IQR: 1–6 days) from first point of contact (email/phone) by the patient. The majority of patients had a fast track evaluation, with limited resource utilisation. CRP and fecal calprotectin were the most com-

mon measures of disease severity performed in patients presenting to the RAC, in 85.2% and 62.5% of patients, respectively. Clostridium difficile stool test and stool culture test were performed in 43.8% and 42.4% of the patients. The frequency of colonoscopy and flexible sigmoidoscopy following the RAC visit were 22.9% and 6.7%. Only a minority of patients underwent CT (7.1%) and MR (1%) imaging. A change in therapy was initiated during the RAC visit in 57% of the patients. Within 30 days from the index visit, only 21 patients of the 261 (19 patients with IBD related symptoms) required an ER visit and 9 patients hospital admission. 9 ER visits were initiated during the RAC visit, 7 other patients had unplanned ER visit due to continuous IBD activity. Only 5 patients who were screened by the RAC physician and deemed not to require an urgent consultation presented at the ER (unplanned ER visit rate were 1.8%, no patient required admission and no IBD activity could be revealed objectively). (see Fig. A1 – online presentation).

4. Discussion

This is the first report on real life comprehensive evaluation of structure, process and outcome indicators on care delivery from a dedicated IBD center in Canada. Results from the present study show that harmonized objective monitoring and accelerated treatment pathways were applied at the MUHC IBD center at referral and during follow-up with special emphasis on providing rapid access and avoiding undesirable outcomes such as steroid dependency, ER visits or emergency hospitalizations/surgeries. Our aim was to provide reference data for comparison of structure, process algorithms and expected outcome indicators in IBD centres in North America with a similar reimbursement/billing environment.

We embarked on objective patient monitoring according to published consensus QI in our IBD center (e.g. assessment of biomarkers and endoscopy before changing the medical strategy, avoiding steroid dependency) [19]. By assessing multiple QIs in our IBD centre, we can demonstrate that through a specialized multifaceted structure (i.e. MUHC IBD Centre) based primarily on dedicated IBD-specialists, IBD-nurses and available referral specialist the care of IBD patients facilitated the delivery of important processes of care

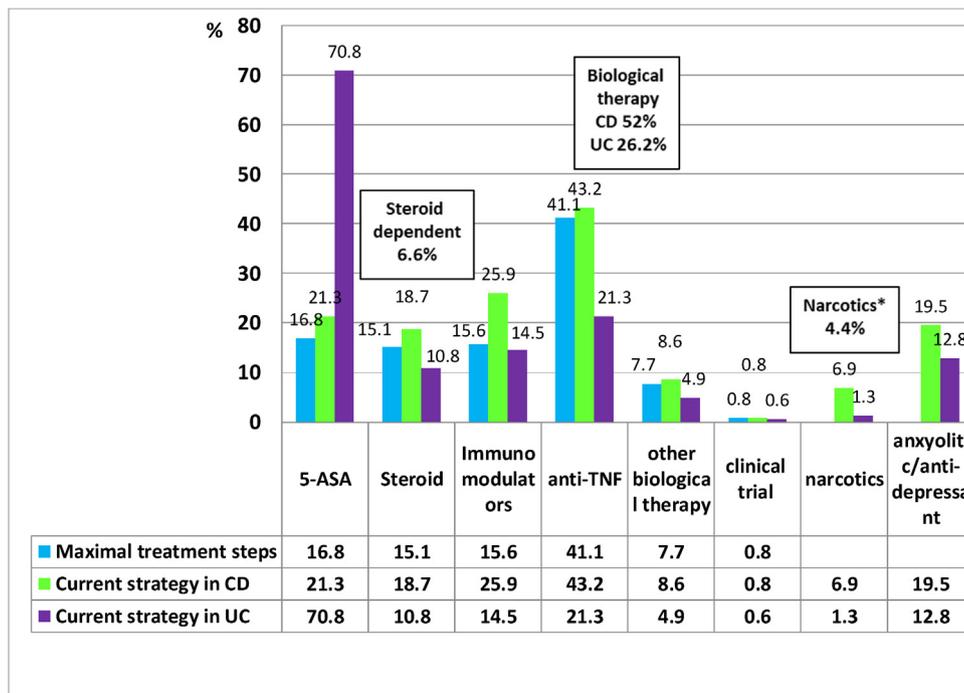


Fig. 4. Therapeutic strategy at index visit: maximal treatment step and current treatment.

which ultimately resulted in favorable outcomes. In a recent Italian survey, the proper availability of a multidisciplinary team/referral specialists has been found to be one of the highest rated ‘unmet need’ among physicians managing IBD [20].

It is important to know the disease phenotype of the IBD cohort expected to receive care in an IBD specific clinic/center. Approximately half of CD patients have extensive and complicated disease, and a similar percentage of UC patients have severe extensive phenotype already at referral after a median 6 year disease duration. Similar data were reported recently from a European IBD center with 62.1% and 49.6% of CD patients having ileocolonic or complicated disease, respectively and 72.1% of UC patients having extensive disease [14]. Another important characteristic is the maximal therapeutic step, which was suggested can be regarded as a proxy marker of disease severity in administrative databases [21]. Almost half of the patients were treated with a biological therapy. In concordance, a similar rate was reported in the European study (47.4%) cited earlier [14]. Of note, these data confirm that a more severe patient phenotype is expected at the IBD centers. In comparison, complicated disease phenotype is expected in approximately one-third of CD patients while the rate of 50% is expected after 20-years of disease duration in population-based cohorts, while the majority of UC patients are expected to have mild-to-moderate left-sided colitis [21–23].

The other important foundation of care delivery in any setting is the harmonized, objective patient monitoring. Of note, in the present study we have shown that patients were objectively evaluated at around referral with almost 80% of patients undergoing ileocolonoscopy and approximately 40% undergoing cross sectional imaging to better characterize the disease phenotype and/or re-evaluate the disease in an active state. Not surprisingly, evaluation by biomarkers (e.g. CRP, CBC) was almost universal at referral, while the underuse of fecal calprotectin as marker can be explained by lack of reimbursement at around the time of referral. Finally, re-evaluation resulted in the change of the therapeutic algorithm in half of the referred patients with half of these receiving biological therapy. Importantly, the re-evaluation resulted in the rethinking of therapy and change of the therapeutic algorithm in a quarter of patients with non-symptomatic disease, highlighting the importance of objective patient assessment.

In keeping with the harmonized objective monitoring theme, patients followed-up in the IBD center had frequent objective monitoring during routine follow-up even in clinical remission, as depicted in Table A2. More than three quarter of the patients had available CBC and CRP testing within 6 months from the index visit, with one third had fecal calprotectin and *C. difficile* testing and 23.8% underwent ileocolonoscopy. Not surprisingly, patients with active disease at the index visit had more diagnostic tests ordered as compared to those patients in remission. In comparison, 45.5% and 51.5% of CD and UC patients respectively underwent endoscopic evaluation while 39.3% of CD patients had an MRI over a 2-year follow-up period in the previously cited European IBD center between 2014–2016 [14]. An extreme example of “mandatory” nationwide harmonized monitoring and care practices was reported from Hungary, where biological therapy can only be dispensed in an IBD center and the sole public insurance company mandates objective monitoring of patients on biological therapy including tracking of clinical scores (CDAI or pMAYO), CRP, CBC and adverse events every 3-months with yearly colonoscopy/cross sectional imaging and TB testing [24].

An important aspect is providing timely access for active patients. It is desirable to avoid emergency room visits and evaluation by an IBD specialists should be preferred. Moreover, ER visits are associated with a large economic burden. In a recent study from Manitoba, Canada, over a three-year period 76% of newly diagnosed IBD cases and 49% of patients already known to have IBD had at

least one ER visit [25]. Interestingly, care received from the same physician was identified as a protective factor against ER visits. Data from the present study show that a rapid access pathway to the IBD center optimizes resource utilization (e.g. greater use of biomarkers, compared to endoscopy, cross-sectional imaging including CT) to reach a therapeutic decision can prevent unplanned ER visits in the majority of patients. Earlier data from an Italian study also presented additional clinical gain by reducing unnecessary hospitalisations, using a dedicated ‘call center’ for IBD patients [26].

There are also other examples that care provided by the specialist is directly associated with better outcomes: e.g. primary care by a gastroenterology specialist was associated with better outcomes and lower mortality in hospitalized UC patients [27].

The third pillar of care delivery is represented by the outcome indicators. It is best to map a variety of different indicators: treatment outcomes (e.g. steroid dependency), need for hospitalisations and major surgeries. For example current steroid use and steroid dependency during follow-up in the present study was even lower than figures published from population-based IBD cohorts [28,29]. However, it is clear that not all hospitalizations or surgeries can be avoided and some may represent medical decision rather than failure. For example, in the present study 25.2% of CD patients and 4% of UC patients had a colectomy/IPAA resective surgery already at referral over a median 6 years of disease duration. A further 26.8% of CD patients and 6.6% of the UC patients required colectomy/IPAA resective surgery during the median 8 years of follow-up at the MUHC IBD center. Though these figures are not low, they are not higher than rates reported 10 years after the disease onset from population-based IBD cohorts representing the full spectrum of IBD patients. [23]. In addition, early limited surgery can be an active therapeutic decision and does not necessarily represent a failure of medical therapy in selected patients [30].

In concordance with findings from the present study, Canadian authors have recently published by using administrative health data in Saskatchewan that patients exposed to an integrated model of care had superior disease outcomes, including lower risk of steroid dependency (HR=0.39), lower surgery risk (HR=0.79) and higher probability of immunomodulatory (HR=1.68) or biological prescription (HR=1.85) in the exposed population in a propensity score-matched model [31].

The strength of the study is the extensive capture of QIs including structural, process and outcome indicators. We believe that several QIs, reflecting different aspects of care delivery, monitoring and decision making processes need to be mapped to objectively evaluate the delivery of care in the center. In addition, harmonized care approach of the physicians was augmented by developing harmonized monitoring pathways. Limitations of the study include the partly retrospective nature and lack of systematic mapping of patient reported outcomes. Despite these limitations, this study provides a strong rationale for standardizing the care of patients with IBD and longitudinal mapping of QIs to provide an optimal care to our IBD patients.

5. Conclusion

Data from the present study confirm the tight harmonized objective monitoring, timely access and accelerated treatment algorithms applied at the MUHC IBD center at referral and during follow-up. QIs mapped in this study can be used as reference data for comparison on structure, process algorithms and expected outcomes for other IBD centres in worldwide and in North America and could contribute to more optimal health resource utilization in present and future IBD centers.

Conflict of interest

None declared.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.dld.2018.11.013>.

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