Understanding attitudes, concerns, and health behaviors of patients with inflammatory bowel disease during the coronavirus disease 2019 pandemic

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Abstract

Background and Aim: The coronavirus disease 2019 (COVID-19) pandemic has led to a rapid shift in care delivery models for patients with inflammatory bowel disease (IBD); however, little is known about patient perceptions during this period. We aimed to prospectively evaluate the attitudes, concerns, and health behavior of IBD patients during COVID-19.

Methods: An online survey was sent to patients from a tertiary IBD Service. The survey included demographic information and questions about the impact of COVID-19, levels of concern caused by COVID-19, perceived risk of IBD medications, medication cessation, and care delivery preferences.

Results: Of 97 respondents (39%), 95 (98%) reported concern about the impact of COVID-19 on their health, and 43% felt their risk of contracting COVID-19 was above average; 62% reported concern about medication-induced COVID-19 risk, and 11% stopped medications because of COVID-19. Patients considered all medications to increase the risk of COVID-19 susceptibility and severity; 45% preferred telehealth while 16% preferred face-to-face clinic reviews. Preference for IBD monitoring tools in decreasing order was blood testing, stool collection, gastrointestinal ultrasound, magnetic resonance enterography, and then colonoscopy.

Conclusions: Patients with IBD are demonstrated to experience concern related to their diagnosis and medications. The insights provided by the survey are informative for a possible “second-wave” of COVID-19 and routine care, including acceptance of telemedicine, preference for non-invasive investigations, and a need for dissemination of information and education.

Introduction

The severe acute respiratory syndrome coronavirus 2, which causes coronavirus disease 2019 (COVID-19), has emerged as a global health crisis. COVID-19 is characterized by fever, respiratory, and gastrointestinal symptoms and can progress to severe disease with respiratory and organ failure.1 The current COVID-19 pandemic is associated with a 1–18% hospitalization rate and an estimated infection fatality ratio of 2.7% in the general population.2

The risk of severe disease and death with COVID-19 increases with age, immunosuppression, and chronic disease on the basis of early data and extrapolation from other coronavirus diseases.2,3 Inflammatory bowel disease (IBD) is a chronic condition that is...
frequently associated with relapsing disease or flares requiring immunosuppressive medications.\textsuperscript{6,7} IBD patients are considered at increased risk of COVID-19 related severe disease and mortality, with a standardized mortality ratio of 1.5–1.8 for IBD patients compared with the general population.\textsuperscript{5,7} IBD flare and subsequent use of systemic steroids is considered a greater risk factor for severe COVID-19 disease than other medications used to induce and maintain remission including thiopurines, methotrexate, and monoclonal antibody medications.\textsuperscript{8} An international prospective IBD COVID-19 registry found an adjusted odds ratio for COVID-19 related death of 11.62 for corticosteroid use; however, no other medication was associated with significantly increased odds of death.\textsuperscript{7,9} Notably, 5-aminosalicylates were associated with severe illness but not death in preliminary analysis, but this finding has not yet been replicated, and the significance of this association remains unclear.\textsuperscript{7} Similar findings were demonstrated in another study in which corticosteroids but not immune-mediated therapy was associated with higher risk of severe COVID-19.\textsuperscript{10}

During this period of uncertainty and changing health advice, citizens in many countries have received directives to self-isolate with quickly evolving policy changes in response to new information. Furthermore, there has been a rapidly implemented shift to digital health-care provision through telemedicine to avoid unnecessary social contact and mitigate the risk of health-care transmission of the virus. In this pandemic setting, patients with IBD may have been burdened by serious health concerns and anxieties, compounded by reduced access to primary and specialist health-care provision. Prior to the COVID-19 pandemic, up to a third of IBD patients were not adherent with prescribed medications.\textsuperscript{11} Given the propensity for self-initiated medication withdrawal during this period, a far high rate of medication nonadherence may be anticipated, placing patients at increased risk of disease flare and steroid use.

A better understanding of the attitudes of IBD patients toward the COVID-19 pandemic will assist in developing high-quality health care and mitigating risk of IBD complications. This information transcends the current pandemic and has future relevance in the face of a second wave of COVID-19 illness and possible future pandemics. The aim of this study is to prospectively survey patients with IBD to understand their attitudes and concerns regarding COVID-19 relevant to their disease, medications, and care delivery preferences.

**Methods**

**Participants.** The participants in this study were sourced from an IBD database of patients known to the Queen Elizabeth Hospital IBD unit, which is a tertiary IBD center caring for >600 patients with IBD, one-third of whom receive biologic therapy. During the COVID 19 pandemic, the Queen Elizabeth Hospital IBD service changed to a default telephone consultation service for all outpatient encounters. A fortnightly newsletter summarizing current society recommendations and guidelines was disseminated electronically to all patients. Endoscopy activity was significantly reduced in March and April of 2020 according to government policy. Point-of-care gastrointestinal ultrasound was provided through the IBD service as a non-invasive IBD activity assessment tool. Gastrointestinal ultrasound is accurate when compared with ileocolonoscopy and can guide management decisions including medication escalation and de-escalation while avoiding endoscopy in many cases.\textsuperscript{12,13} All patients with available email addresses (42% of cohort) were contacted for inclusion in the study on April 21, 2020. The project was reviewed and approved by the Central Adelaide Local Health Network human research ethics committee prior to commencement.

**Survey and distribution.** The survey included demographic information, IBD phenotype and medications, and perceived risk of COVID19 including risk associated with IBD and medication use, whether participants had considered or already stopped medications because of COVID19 and who they discussed this with, perceived risk of specific IBD medications for infection and serious illness/death associated with COVID19, current level of social distancing/isolation, employment conditions and preferences for receiving IBD care during the COVID19 pandemic including information distribution, and the use of telehealth and monitoring tools for assessing IBD. Questions used a binary yes/no or Likert scale format. Monitoring tool preference was measured on a 5-point Likert scale. The full list of survey questions is available as a supplementary file (Data S1). The survey was sent to recorded patient email addresses using an online survey platform, and a reminder email was sent to nonrespondents 10 days after the initial invitation to participate.

**Statistical analysis.** Descriptive and summary statistics were used to describe the demographic and clinical characteristics of respondents. Continuous variables were summarized with mean and standard deviations. The Wilcoxon sign-rank test was used to compare assessment modality preference as normality assumptions have not met any responses. All statistical calculations were performed using STATA V14 (StataCorp, TX, USA).

**Results**

**Participant information.** There were 251 email invitations sent to patients with IBD, and 97 responses were received (39%) between April 21 and May 22, 2020. Demographic, phenotypic, and medication data of respondents are presented in Table 1. Eight patients (13%) were taking prednisone at the time of the survey, 40 patients (60%) were on immunomodulator therapy, and 51 patients (53%) were on biologic medications. Nine patients (9%) were not on any IBD medications. All patients reported some level of social distancing as a result of COVID-19; 4 (4%) were avoiding large gatherings, 26 (29%) continued to work but avoided unnecessary social exposure, 54 (60%) were only going out for essential services, and 6 (7%) had completely self-isolated. Of those employed at the time of the survey, 42 (66%) described their employer as extremely supportive of any need to socially distance or isolate because of IBD, 15 (25%) were somewhat supported, and 6 (9%) did not feel supported.

**Perceived risk of coronavirus disease 2019.** Of the patients, 38 (42%) were very or extremely concerned about the impact of COVID-19 on their personal health while only 2 (2%) were not at all concerned. In those 38 expressing concern, 2 were on no
IBD patient concerns during COVID-19

Table 1  Demographic and clinical characteristics of 97 respondents

| Characteristic | No. (%) |
|----------------|---------|
| Age (median, range) | 49, 17–77 |
| Current smokers n (%) | 14 (14%) |
| IBD phenotype | |
| Crohn’s disease n (%) | 57 (59%) |
| Ulcerative colitis n (%) | 38 (39%) |
| Unsure/indeterminate n (%) | 2 (2%) |
| Current medications | |
| Prednisolone n (%) | 8 (13%) |
| Budesonide n (%) | 3 (5%) |
| 5-Aminosalicylates n (%) | 35 (49%) |
| Rectal therapy n (%) | 10 (17%) |
| Thiopurines n (%) | 35 (51%) |
| Methotrexate n (%) | 5 (9%) |
| Infliximab n (%) | 19 (30%) |
| Adalimumab n (%) | 10 (16%) |
| Golimunab n (%) | 2 (4%) |
| Vedolizumab n (%) | 14 (23%) |
| Ustekinumab n (%) | 9 (15%) |
| Tofacitinib n (%) | 1 (2%) |
| Combination medication use | |
| Thiopurine and biologic agent | 18 (19%) |
| Methotrexate and biologic agent | 4 (4%) |
| Prednisolone and biologic agent | 2 (2%) |
| Prednisolone, thiopurine, and vedolizumab | 1 (1%) |

IBD, inflammatory bowel disease.

medications, 4 were on aminosalicylates, 11 were on steroids or immunomodulators, 12 were on biologics, and 9 were on combination therapy with a biologic agent and immunomodulatory. Personal risk of catching COVID-19 was considered above average by 39 (43%), average by 32 (36%), and below average by 19 (21%). IBD caused additional concern about COVID-19 a lot or a great deal in 34 (38%), moderately in 27 (30%), and a little or not at all in 29 (32%). Of the patients, 50 (56%) expressed moderate to great concern of an IBD flare. When questioned about perceived risk of individual medications for susceptibility to COVID-19, lowest to highest risk was attributed to 5-aminosalicylates, budesonide, tofacitinib, vedolizumab, steroids, ustekinumab, thiopurines, methotrexate, and anti-tumor necrosis factor-α (anti-TNFα) medications (Table 2). For perceived risk of individual medications for severe illness or death from COVID-19, lowest to highest risk was attributed to 5-aminosalicylates, tofacitinib, budesonide, vedolizumab, steroids, thiopurines, methotrexate, anti-TNFα medications, and ustekinumab (Table 3). Of the participants, 65 (73%) indicated that they would like to receive more information about the current understanding of how IBD medications may affect COVID-19 risk.

Care delivery preferences. Of the participants, 74 (82%) indicated that they would like to receive email updates regarding coronavirus and IBD. Preference for care delivery was by telephone or teledicine in 40 (45%) and face-to-face clinic review in 14 (16%), and no preference indicated by 35 (39%). When questioned about preference for IBD monitoring tools, the mean score (±standard deviation) was greatest for blood testing 3.92 (±0.96), stool collection 3.28 (±1.08), and gastrointestinal ultrasound 3.28 (±0.99); all of which were significantly greater than mean score for magnetic resonance enterography 2.95 (±0.97) and colonoscopy 2.75 (±1.16) (P < 0.002 for each comparison).

Table 2  Perceived risks ranked 1 (no increase in risk) to 4 (great increase in risk) of inflammatory bowel disease medications for catching coronavirus disease 2019

| Medication | No or small increase in risk (1–2) | Moderate or great increase in risk (3–4) | Mean value |
|------------|----------------------------------|--------------------------------------|------------|
| 5-ASAs     | 31 (79%)                         | 8 (21%)                             | 1.66 (1.03) |
| Budesonide | 8 (67%)                          | 4 (33%)                             | 2.08 (1.16) |
| Tofacitinib| 6 (60%)                          | 4 (40%)                             | 2.1 (1.1)  |
| Vedolizumab| 12 (57%)                         | 9 (43%)                             | 2.15 (1.14) |
| Steroids   | 19 (54%)                         | 16 (46%)                            | 2.19 (1.24) |
| Ustekinumab| 10 (56%)                         | 8 (44%)                             | 2.56 (1.10) |
| Thiopurines| 16 (34%)                         | 31 (66%)                            | 2.66 (1.04) |
| Methotrexate| 8 (40%)                         | 12 (60%)                            | 2.8 (1.20)  |
| Anti-TNFα  | 12 (35%)                         | 22 (65%)                            | 2.85 (1.01) |

5-ASA, 5-aminosalicylates, anti-TNFα, anti-tumor necrosis factor-α medications.
Table 3  Perceived risks ranked 1 (no increase in risk) to 4 (Great increase in risk) of IBD medications for developing severe illness or death from coronavirus disease 2019

| Medication        | No or small increase in risk (1–2) | Moderate or great increase in risk (3–4) | Mean value |
|-------------------|------------------------------------|------------------------------------------|------------|
| 5-ASAs            | 23 (74%)                           | 8 (26%)                                  | 1.74 (0.93) |
| Tofacitinib       | 3 (43%)                            | 4 (67%)                                  | 2.15 (1.07) |
| Budesonide        | 6 (46%)                            | 7 (64%)                                  | 2.31 (1.32) |
| Vedolizumab       | 9 (47%)                            | 10 (53%)                                 | 2.4 (1.07)  |
| Steroids          | 17 (49%)                           | 18 (51%)                                 | 2.51 (1.09) |
| Thiopurines       | 14 (36%)                           | 25 (64%)                                 | 2.77 (0.93) |
| Methotrexate      | 6 (33%)                            | 12 (67%)                                 | 2.78 (1.06) |
| Anti-TNFα         | 9 (21%)                            | 22 (79%)                                 | 2.87 (0.92) |
| Ustekinumab       | 5 (31%)                            | 11 (69%)                                 | 2.88 (1.02) |

5-ASA; 5-aminosalicylates, anti-TNFα; anti-tumor necrosis factor-α medications.

Discussion

This survey of 97 patients with IBD provides an important insight as to the attitudes, concerns, and health behavior of IBD patients during the height of the COVID-19 pandemic in Australia. Patients with IBD are demonstrated to experience greater risk than the general population with IBD and the general population.7 Provision of accurate and up-to-date information may have reassured patients and avoided inappropriate medication cessation.

Patients with IBD were shown to overestimate risk for most medications in the setting of the COVID-19 pandemic. The risks of thiopurine therapy, methotrexate, and anti-TNFα agents were overestimated by many respondents as best evidence is that there is no significant increase in risk associated with these agents, aside from when used as combination therapy.8–15 However, in parallel to routine care, patients tended to underestimate the risks associated with corticosteroid therapy, which has been shown to impart risk of severe COVID-19 disease.7,10,16 Although it is acknowledged that a rapidly evolving pandemic situation prevented accurate appraisal of IBD medication risk for COVID-19, survey data illustrate the importance of provision of current and accurate information so as to help mitigate medication-related anxiety and prevent inappropriate medication cessation.

A favorable response by patients toward drastic changes in care delivery during the COVID-19 pandemic was demonstrated, in particular a shift toward telemedicine and non-invasive disease assessment. Telehealth consultation was preferred by most but not all patients with IBD during the height of the COVID-19 pandemic. Telehealth has been long proposed as a mechanism for effective delivery of IBD care, particularly for patients in remote settings.20 However, until the advent of the pandemic, delivery of telemedicine has not matched enthusiasm. The rapid increase in delivery and acceptance of telemedicine as an efficient means of achieving safe and convenient care to patients with IBD must be considered a silver lining of the current situation. Indeed, current guidelines support ongoing consultation via telemedicine for at least one-third of patients beyond the COVID-19 pandemic peak.21,22

Given that not all patients consider telemedicine favorable, care delivery should be tailored and personalized where possible, so as to ensure the most satisfying outcomes for patients and clinicians. This survey demonstrated a significant preference for non-invasive assessment of IBD, which parallels routine practice.13,23 While it is unsurprising that patients prefer monitoring tools that are less invasive and do not require bowel preparation, the finding is in keeping with previous studies and is important to consider when delivering a quality care model.23–25

Current expert opinion supports utilization of non-invasive tools for treat-to-target strategy both during and after the initial peak of the COVID-19 pandemic.21 Notably, respiratory syndrome coronavirus 2 is detectable in stool in 29% of cases, and fecal viral shedding may persist longer than respiratory shedding.26,27

In the current pandemic, stool collection presents a theoretical

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increase in risk to patients and laboratory staff not assessed in this survey.

These strengths of this study include the fact that it is the first in Australia to evaluate perceptions of patients with IBD at the height of the COVID-19 pandemic revealing important data as to how to best manage a second wave or future pandemic. The study was limited by the relatively small sample size and risk of responder bias with a response rate of 39%, although this is consistent with many epidemiological survey response rates.\(^2\)\(^8\)\(^9\) The participants all resided in an Australian state with low COVID-19 case numbers, which may limit the generalizability of results to international areas with high prevalence of COVID-19 infection. Furthermore, the survey was administered 4 weeks into the COVID-19 care model meaning that some respondents had already been reviewed by telehealth and provided with electronic information and employer letters while others had not, which may have affected how respondents answered many of the questions.

In summary, this study reveals the health-related concerns experienced by patients with IBD during the height of the COVID-19 pandemic in Australia. The insights provided by the survey are informative for a possible second wave of COVID-19, including acceptance of telemedicine, safe delivery of accessible non-invasive investigations as colonoscopy surrogates, and a need for dissemination of information and education. These lessons learned may well transcend the pandemic period and lead to shifts in care delivery toward a more patient-centered and efficient model.

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Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Data S1. Supporting information.