




# The Impact of COVID-19 on Health Anxiety and Perceived Stress Among Persons with IBD: A Population-representative Study

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## Abstract

**Background:** The Corona Virus Immune Disease-2019 (COVID-19) pandemic has broadly impacted the mental health of individuals worldwide, especially with restrictions including social distancing and quarantining. Persons with IBD are at increased risk of mental health disorders. The aim was to understand how the COVID-19 pandemic affected adults with a chronic health issue, inflammatory bowel disease (IBD), using a population-based sample.

**Methods:** A survey study in Manitoba was conducted during the second COVID-19 wave in autumn 2020. We assessed proportions of health anxiety and perceived stress using validated measures, as well as stressors during the COVID-19 pandemic. We used univariable and multivariable logistic regression analysis to assess predictors of perceived stress and health anxiety.

**Results:** A total of 1,384 (47.1%) persons responded, with a mean age of 58.0, and 46.9% had Crohn's disease. Almost three quarters (73.7%) had increased stress, with 37.7% having increased stress about their IBD, and 33.6% worried about their IBD worsening. 46.0% felt increased stress about accessing their doctor or nurse, and 56.5% felt they had good access to their gastroenterologist. Elevated stress and health anxiety were seen in 63.5% and 17.2% of respondents, respectively. Younger age and being on immune-modifying therapy (IMT) was predictive of increased health anxiety and stress. Longer IBD duration was associated with decreased stress, including those on IMT.

**Conclusion:** Persons with IBD reported high rates of stress and health anxiety early in the COVID-19 pandemic, especially among those on IMT. It will be important to determine how this evolved over time and to what extent this impacted on disease course.

**Key words:** COVID-19; IBD; mental health; survey study.

## Introduction

The Corona Virus Immune Disease-2019 (COVID-19) pandemic has globally impacted public health and the world economy. In the context of this worldwide pandemic, there have also been mental health sequelae, including escalating rates of anxiety and depression.<sup>1,2</sup> For individuals with chronic disease or other health concerns, psychological distress is related, in part, to challenges in accessing medical care including procedures, hospitalizations, and/or surgeries that would have otherwise been warranted in their disease management.<sup>3</sup>

Inflammatory bowel disease (IBD), which includes Crohn's disease (CD) and ulcerative colitis (UC), is a chronic immune-mediated inflammatory disease often requiring surgical and medication management. It is well established by our team and others that persons with IBD have significantly higher rates of depression and anxiety than the general population and that mental health symptoms exacerbate the disease.<sup>4–8</sup>

Given the strong relationship between mental and physical health in IBD, increased mental health challenges are anticipated to translate to worsening disease outcomes. An online survey in Australia of persons with IBD reported 34.9% and 32.0% of people without a prior mental health diagnosis exhibiting new symptoms of depression and anxiety, respectively.<sup>9</sup> A US-based cross-sectional survey of persons with IBD found the majority had increased anxiety from early in the pandemic, which was associated with an increase in gastrointestinal symptoms.<sup>10</sup>

There is a need to identify the extent to which those with IBD experienced new mental health problems and had exacerbations of existing comorbid psychiatric conditions. This will help us understand how those with chronic diseases, such as IBD, have responded to the ongoing COVID-19 pandemic, and their changing care needs, in addition to guiding health system response for future pandemic waves or other public health crisis. While the mental health of persons with

IBD has been studied throughout the COVID-19 pandemic, none of these have been population-based studies, nor have they assessed broader variables such as economic impact, health stressors, and access to the care team or specialist. Our aim was to determine the mental health impact of the COVID-19 pandemic on adults with IBD in Manitoba during the first year of the pandemic.

## Materials and methods

This is a cross-sectional study whereby participants of the population-based University of Manitoba IBD Research Registry (UMIBDRR),<sup>11</sup> ( $n = 2,940$ ), where addresses are regularly being updated, were invited to participate in a survey regarding their experiences with COVID-19 during autumn 2020, just prior to and during the second pandemic wave in Manitoba. Approximately 45% of persons with IBD in Manitoba are enrolled in the UMIBDRR.<sup>7,12</sup> This study was approved by the Research Ethics Board at the University of Manitoba.

A letter of introduction, consent form, and paper survey were mailed to registry participants, inviting their participation and providing the option to complete the survey via the provided paper copy or by accessing an online link to complete the survey through the REDcap platform. Using a modified Dillman method<sup>13</sup> we sent email or letter reminders, depending on available contact information, to complete the survey to those who had not responded at 2 and 4 weeks. If information was missing from a survey, we attempted to contact that respondent for their responses. Survey data were kept confidential as names were removed from responses once uploaded, and were only accessible by our statistician.

## Measures

The survey included background sociodemographic and disease information (e.g., phenotype, medication use), employment status pre- and peri-pandemic including changes in hours and income, and questions regarding healthcare access and use. Mental health needs and access to care were assessed using the Canadian Community Health Survey (2018) questions, with validated measures of perceived stress scale (based on perceived stress scale-10)<sup>14</sup> and health anxiety (based on short health anxiety inventory-14).<sup>15</sup> This is included in the supplementary material.

## Outcomes and predictors

We included two main predictors of mental health: health anxiety and perceived stress. Perceived stress was defined using the PSS-10 survey. A score of greater than 13 was indicative of elevated perceived stress. Health anxiety was defined using the SHAI-14 survey. A score of greater than 17 was positive for elevated health anxiety.

Possible predictors of elevated perceived stress and elevated health anxiety included demographic and IBD-related variables such as age (17–64, 65+), disease diagnosis (CD vs. UC), disease duration of IBD in years (0–10, 1–30, 30+), use of any IBD-therapy, and use of any immune-modifying therapy (including corticosteroids, azathioprine/6-mercaptopurine, methotrexate, biologic therapy including infliximab, adalimumab, vedolizumab, ustekinumab, or tofacitinib).

Pandemic-related predictor variables for stress and health anxiety included the presence of gastrointestinal symptoms, work-from-home status, the status of children at home, decreased work hours during the pandemic if the person was an essential worker, and if they were a frontline worker.

We also describe relevant stressors persons with IBD experienced at this point in time of the pandemic across multiple dimensions, including their disease, access to therapy, or access to care.

## Statistical analysis

Among survey respondents, we included people who were diagnosed with either CD or UC in the final analysis. Descriptive statistics were presented as means and standard deviations (SD), and percentages. Bivariate analysis was conducted for CD versus UC; persons with IPAA along with those who were unaware of their phenotype, were excluded from these analyses due to their small numbers. For bivariate analyses, we used the Student's *t* test for continuous variables and Fisher's exact and Chi-square tests for categorical variables, where appropriate. In order to assess the association between predictors of perceived stress and health anxiety, we used both univariate and multivariable logistic regression analysis. Multivariable models included COVID-19-related, demographic, and IBD-related variables (age, disease phenotype, disease duration, and being on immune-modifying therapies). A *P* value of <0.05 was considered to be statistically significant. All data analyses were performed using SAS Software (version 9.4).

## Results

Of 2,940 participants in the registry with current contact information, there were 1,384 respondents, reflecting a 47.1% response rate. Characteristics of respondents compared to non-respondents from the IBD registry are shown in [Table 1](#). Respondents are more likely to be female and married. We do not have data on IBD disease duration or therapy use on non-respondents hence we could not compare these variables.

### Patient characteristics

Those who participated in the study were more likely to be female, and to be married. Mean age and IBD phenotype were similar between the two groups. Almost half of the respondents, 46.9% (649) had CD, 46.7% (647) had UC, and 2.2% had an ileoanal pouch. Since the majority of respondents to the survey had either CD or UC ( $n = 1,296$ ), the majority of the analyses were therefore performed on these people. The mean age was 58.0 (SD 13.9), the age range was 17–91 years old, and 40.6% reported male gender ([Table 2](#)). Distribution of age and gender were similar between CD and UC; persons with UC had a shorter duration of disease by a few years on average, compared to those with CD. The majority of respondents (76.8%) had children, with 44.2% of them living at home.

A total of 58.5% of respondents were working pre-pandemic, either part-time or full-time, of which 90.5% of those working pre-pandemic were still working during the pandemic. Of those working, almost half (49.6%) were doing so from home. The majority (65.0%) of workers self-identified as an essential worker, and 20.6% of workers self-identified as frontline workers. Eight percent reported losing

**Table 1.** Comparison of research registry survey respondents and non-respondents.

	Respondents ( <i>n</i> = 1,384)	Non-respondents ( <i>n</i> = 1,556)	<i>P</i> value
Mean age, years (SD)	58.0 (13.9)	57.9 (14.5)	0.9553
Male gender (%)	40.4	45.9	<b>0.0047</b>
Disease phenotype (%)			
Crohn's disease	46.9	49.8	0.1918
Ulcerative colitis	46.7	45.1	—
Ileo-anal pouch	2.2	3.0	—
Mean duration of IBD, years (SD)	24.8 (12.8)	Not available	Not available
Marital status (%)	—	—	<b>&lt;0.001</b>
Married	70.6	58.2	
Common-law	8.0	5.6	
Divorced	6.0	6.0	
Separated	1.8	3.2	
Widowed	4.1	1.4	
Never married	8.8	25.4	
IBD therapy (%)			
Prednisone	3.5	Not available	Not available
Entocort	1.9	—	—
5-ASA	29.4	—	—
Enemas (5-ASA or steroid)	2.1	—	—
Azathioprine	12.9	—	—
Methotrexate	3.7	—	—
Infliximab	10.5	—	—
Adalimumab	7.4	—	—
Vedolizumab	3.9	—	—
Ustekinumab	3.5	—	—
Tofacitinib	0.1	—	—
Not on any therapy	34.9	—	—

Note: Bold= statistical significance at  $P \leq 0.05$ .

their job during the pandemic, 11.0% experienced decreased hours, and 6.7% experienced less pay. Because of income loss, 8.8% of respondents had applied for unemployment insurance (EI) during the pandemic. A decrease in total household income was reported by 21.9% of respondents with only a small proportion of 2.5% reporting an increase.

In terms of IBD therapy, 32.2% of respondents were not taking any medications for their IBD, while 38.7% were on some form of immune-modifying therapy. CD patients were more likely to be on immune-modifying therapies compared with UC patients, while UC patients were more likely to be on 5-ASA therapies. Of persons using some form of IBD therapy, 10.8% of respondents adjusted their IBD medications on their own, with UC respondents being more likely to do so than CD respondents; 12.6% of respondents had their physician adjust their IBD medications.

A mental health disorder, such as depression, anxiety disorder, bipolar disorder, schizophrenia, or PTSD was self-reported by 21.3% of respondents; 78.0% of those indicating a mental-health diagnosis were taking medications for their mental health concerns. Overall, 12.1% of respondents felt they needed help from a mental health professional during the COVID-19 pandemic to date, but only 54.6% of those felt they had adequate access to a mental health professional (Table 3).

The greatest distress during the pandemic was worry about a family member's health (42.6%), followed by contracting COVID-19 (32.6%) (noting multiple responses were allowed). Nearly three quarters (73.7%) of respondents completely or somewhat agreed that stress had increased during the COVID-19 pandemic, with 37.7% indicated increased stress about their IBD, 33.6% were extremely or somewhat worried about their IBD worsening (more so in CD than UC), 37.5% felt increased stress about their finances, 44.6% felt increased stress about their workplace, 73.4% were extremely or somewhat worried about a family member getting sick from COVID-19, and 86.9% felt increased stress about their family's well-being. A total of 41.7% were worried about their health worsening, and 58.5% were extremely or somewhat worried about getting sick from COVID-19.

With regard to health care, 46.0% felt increased stress about accessing their doctor or nurse, while 21.1% had increased stress about accessing their prescription IBD medications. Overall, however, 64.2% felt they had good access to their doctor/nurse to discuss their IBD, and 67.2% felt they had good access to discuss their non-IBD healthcare issues. More than half (56.5%) felt they had good access to their gastroenterologist, although that still left a large proportion who did not perceive ready access.

**Table 2.** Characteristics of study participants, stratified by disease subtype.

	Total ( <i>n</i> = 1,296)	Crohn's disease ( <i>n</i> = 649)	Ulcerative colitis ( <i>n</i> = 647)
Mean age, years (SD)	58.0 (13.90), range	57.7 (13.6), range	58.3 (14.2), range
Age, % ( <i>n</i> )	17–91	20–90	17–91
17–64	64.6 (837)	66.1 (429)	63.1 (408)
65+	35.4 (459)	33.9 (220)	36.9 (239)
Male gender, % ( <i>n</i> )	40.4 (524)	38.8 (252)	42.0 (272)
Mean duration of IBD, years (SD)	24.7 (12.8), range 1–71	27.1 (12.9), range 1–71	22.4 (12.2), range 1–57
Duration of IBD, % ( <i>n</i> )			
0–10	16.2 (198)	12.3 (76)	20.3 (122)
11–30	48.4 (591)	43.9 (271)	53.2 (320)
30+	35.3 (431)	43.9 (271)	26.6 (160)
Medications, % ( <i>n</i> )			
On no IBD therapy	32.2 (417)	34.7 (225)	29.7 (192)
5-ASA therapy (oral, supp, enema)	33.3 (432)	15.4 (100)	51.3 (332)
On immune-modifying IBD therapies? (infliximab, adalimumab, vedolizumab, ustekinumab, tofacitinib, azathioprine, methotrexate, or prednisone)	38.7 (502)	51.6 (335)	25.8 (167)
Were you on an intravenous therapy for your IBD (i.e., infliximab or vedolizumab)?, % ( <i>n</i> ) Yes	14.9 (193)	16.8 (109)	13.0 (84)
Pre-pandemic employment status			
Full-time	44.1 (572)	44.7 (290)	43.6 (282)
Part-time	14.4 (186)	13.4 (87)	15.3 (99)
Full-time student	1.4 (18)	1.1 (7)	1.7 (11)
Part-time student	0.6 (8)	0.6 (4)	0.6 (4)
Unemployed and looking for work	0.9 (11)	0.3 (2)	1.4 (9)
Unemployed and not looking for work	1.4 (18)	1.7 (11)	1.1 (7)
Retired	38.4 (497)	38.2 (248)	38.5 (249)
Disability	4.4 (57)	5.7 (37)	3.1 (20)
Homemaker	3.4 (44)	3.1 (20)	3.7 (24)
If you were working pre-pandemic (part- or full-time), were you working during the pandemic? % ( <i>n</i> )	90.5 (686)	89.4 (337)	91.6 (349)
Of those who were working, during the pandemic, were you working from home? <sup>a</sup> % ( <i>n</i> )	49.6 (340)	53.1 (179)	46.1 (161)
Of those who were working, were you considered an essential worker? % ( <i>n</i> )			
Yes	65.0 (446)	65.3 (220)	64.8 (226)
Unsure	12.2 (84)	12.5 (42)	12.1 (42)
Of those who were working, were you considered a frontline worker?			
Yes	20.6 (141)	16.9 (57)	24.1 (84)
Unsure	10.1 (69)	9.8 (33)	10.3 (36)

<sup>a</sup>Denominator included only included people who were working during the pandemic.

### Health anxiety

Elevated health anxiety was evident for 17.2% of respondents (SHAI > 17). From the multivariable analysis, older age (aOR 0.63, 95% CI 0.42–0.93) was associated with lower odds of health anxiety, while being on immune-modifying therapy (aOR 1.60, 95% CI 1.15–2.22), and the presence of gastrointestinal symptoms (aOR 2.88, 95% CI 2.08–3.99), were associated with increased odds of health anxiety (Table 4). Working from home, having children at home, having fewer work hours due to COVID-19, or being a frontline worker, were not associated with health anxiety.

### Perceived stress

Elevated stress was evident for 63.5% of respondents, based on PSS scores > 13. On multivariable analysis, the presence of gastrointestinal symptoms (aOR 2.37, 95% CI 1.83–3.07), working from home (aOR 1.41, 95% CI 1.03–1.92), and being a frontline worker (aOR 1.94, 95% CI 1.22–3.09), were all associated with increased odds of perceived stress (Table 5). In those with a short disease duration of IBD (0–10 years), the odds of perceived stress were much greater for those on immune-modifying therapy, compared to those not on immune-modifying therapy. When disease duration was long (30+ years), IMT had very little impact on the odds of perceived stress.

**Table 3.** Survey results of study participants, stratified by disease subtype.

	Total (n = 1,296)	Crohn's disease (n = 649)	Ulcerative colitis (n = 647)	P value <sup>o</sup>
How many people do you live with? % (n)				
Live alone	13.0 (169)	14.6 (95)	11.5 (74)	0.0980**
1	49.8 (645)	48.5 (315)	51.1 (330)	—
2	15.7 (203)	16.2 (105)	15.2 (98)	—
3	13.9 (180)	14.6 (95)	13.2 (85)	—
4+	7.6 (98)	6.0 (39)	9.1 (59)	—
Do you have children? % (n)				
Yes	76.8 (995)	75.2 (488)	78.4 (507)	0.1884
For those with children:				
Do your children live with you? % (n)				
Yes	44.2 (440)	44.9 (219)	43.6 (221)	0.7016
If your children live with you, were they at home during the pandemic? % (n)				
Yes	76.4 (336)	76.7 (168)	76.0 (168)	0.7877
Did you experience the loss of your job during the COVID pandemic? % (n)	8.1 (105)	8.9 (58)	7.3 (47)	0.3087
Did you experience decreased hours at work because of the COVID pandemic? % (n)	11.0 (142)	9.7 (63)	12.2 (79)	0.1556
Did you experience less pay due to the COVID-19 pandemic? % (n)	6.7 (87)	5.4 (35)	8.0 (52)	0.0598
Total household income				
<\$20,000	4.1 (53)	4.5 (29)	3.8 (24)	0.6603**
\$20,000–\$49,999	18.6 (238)	20.0 (129)	17.1 (109)	—
\$50,000–\$74,999	18.1 (232)	17.2 (111)	19.0 (121)	—
\$75,000–\$99,999	15.1 (193)	15.4 (99)	14.8 (94)	—
\$100,000+	31.5 (403)	30.1 (194)	32.8 (209)	—
Prefer not to answer	12.7 (162)	12.7 (82)	12.6 (80)	—
Has your total household income (compared to pre-pandemic)				
Increased	2.5 (32)	2.5 (16)	2.5 (16)	0.8201
Decreased	21.9 (284)	22.7 (147)	21.2 (137)	—
Missing/remained the same	75.6 (980)	74.9 (486)	76.4 (494)	—
Have you applied for income support (EI) due to loss of income during COVID-19 pandemic?	8.8 (114)	10.6 (69)	7.0 (45)	0.0647
No answer OR retired/homemaker	4.5 (58)	4.3 (28)	4.6 (30)	—
I felt general increased stress				
Completely/somewhat agree	73.7 (952)	74.6 (484)	72.3 (468)	0.5818
Neither	11.4 (147)	11.1 (72)	11.6 (75)	—
Somewhat/completely disagree	14.9 (192)	13.9 (90)	15.8 (102)	—
I felt increased stress about my IBD				
Completely/somewhat agree	37.7 (486)	40.4 (261)	34.9 (225)	0.0839
Neither	23.6 (304)	23.5 (152)	23.6 (152)	—
Somewhat/completely disagree	38.8 (500)	36.1 (233)	41.5 (267)	—
I felt increased stress about my finances				
Completely/somewhat agree	37.5 (482)	36.4 (234)	38.5 (248)	0.0168
Neither	19.3 (248)	22.4 (144)	16.2 (104)	—
Somewhat/completely disagree	43.3 (557)	41.2 (265)	45.3 (292)	—
I felt increased stress about my workplace				
Completely/somewhat agree	44.6 (547)	42.7 (262)	46.5 (285)	0.3264
Neither	15.9 (195)	17.9 (110)	13.9 (85)	—
Somewhat/completely disagree	29.4 (361)	29.5 (181)	29.4 (180)	—
Retired	9.9 (121)	9.8 (60)	10.0 (61)	—
Homemaker	0.2 (3)	0.2 (1)	0.3 (2)	—
I felt increased stress about my family's well-being				
Completely/somewhat agree	86.9 (1,113)	88.4 (565)	85.4 (548)	0.2693
Neither	5.5 (71)	4.9 (31)	6.2 (40)	—
Somewhat/completely disagree	7.6 (97)	6.7 (43)	8.4 (54)	—



Table 3. Continued

	Total (n = 1,296)	Crohn's disease (n = 649)	Ulcerative colitis (n = 647)	P value <sup>s</sup>
I felt increased stress about accessing my doctor or nurse				
Completely/somewhat agree	46.0 (592)	48.4 (310)	43.7 (282)	0.2116
Neither	22.5 (289)	21.1 (135)	23.8 (154)	—
Somewhat/completely disagree	31.5 (405)	30.5 (195)	32.5 (210)	—
I felt increased stress about accessing my prescription IBD meds				
Completely/somewhat agree	21.1 (263)	22.9 (143)	19.2 (120)	0.0752
Neither	25.5 (319)	26.9 (168)	24.2 (151)	—
Somewhat/completely disagree	53.4 (667)	50.2 (314)	56.6 (353)	—
I felt there was good access to my doctor or nurse to discuss my IBD				
Completely/somewhat agree	64.2 (821)	64.6 (414)	63.8 (407)	0.4011
Neither	21.1 (270)	19.5 (125)	22.7 (145)	—
Somewhat/completely disagree	10.5 (134)	11.2 (72)	9.7 (62)	—
Does not have doctor/nurse	4.2 (54)	4.7 (30)	3.8 (24)	—
I felt there was good access to my gastroenterologist to discuss my IBD				
Completely/somewhat agree	56.5 (711)	60.5 (384)	52.4 (327)	0.0083
Neither	19.9 (251)	17.2 (109)	22.8 (142)	—
Somewhat/completely disagree	8.4 (106)	9.0 (57)	7.9 (49)	—
Does not have gastroenterologist	15.2 (191)	13.4 (85)	17.0 (106)	—
I felt there was good access to my doctor or nurse to discuss my non-IBD health care issues				
Completely/somewhat agree	67.2 (863)	67.6 (435)	66.8 (428)	0.2883
Neither	16.1 (207)	16.0 (103)	16.2 (104)	—
Somewhat/completely disagree	13.1 (168)	12.0 (77)	14.2 (91)	—
Does not have doctor/nurse	3.7 (47)	4.5 (29)	2.8 (18)	—
How worried were you about childcare? <sup>a</sup>				
Extremely worried	15.0 (60)	12.9 (26)	17.3 (34)	0.2365
Somewhat worried	20.3 (81)	18.3 (37)	22.3 (44)	—
A little worried	9.3 (37)	8.4 (17)	10.2 (20)	—
Not at all	55.4 (221)	60.4 (122)	50.3 (99)	—
How worried were you about job stability? <sup>b</sup>				
Extremely worried	9.5 (102)	9.6 (52)	9.4 (50)	0.8346
Somewhat worried	16.6 (178)	16.0 (86)	17.3 (92)	—
A little worried	18.7 (200)	18.0 (97)	19.4 (103)	—
Not at all	55.2 (591)	56.4 (304)	53.9 (287)	—
How worried were you about financial stability?	13.4 (167)	13.2 (83)	13.5 (84)	0.6763
Extremely worried				
Somewhat worried	17.8 (222)	18.6 (117)	16.9 (105)	—
A little worried	27.9 (349)	26.6 (167)	29.3 (182)	—
Not at all	41.0 (512)	41.7 (262)	40.3 (250)	—
How worried were you about your IBD worsening?				
Extremely worried	8.9 (113)	9.4 (60)	8.4 (53)	0.0149
Somewhat worried	24.7 (313)	28.3 (180)	21.1 (133)	—
A little worried	26.6 (336)	25.6 (163)	27.5 (173)	—
Not at all	39.8 (503)	36.6 (233)	42.9 (270)	—
How worried were you about your health worsening?				
Extremely worried	13.8 (174)	13.5 (86)	14.1 (88)	0.0915
Somewhat worried	27.9 (352)	31.0 (197)	24.8 (155)	—
A little worried	29.3 (370)	28.5 (181)	30.2 (189)	—
Not at all	29.0 (366)	27.0 (172)	31.0 (194)	—
How worried were you about getting sick from COVID-19?				
Extremely worried	24.5 (311)	24.5 (157)	24.4 (154)	0.3009
Somewhat worried	34.0 (432)	34.7 (223)	33.2 (209)	—
A little worried	30.0 (381)	30.8 (198)	29.1 (183)	—
Not at all	11.6 (148)	10.0 (64)	13.3 (84)	—

Table 3. Continued

	Total (n = 1,296)	Crohn's disease (n = 649)	Ulcerative colitis (n = 647)	P value <sup>a</sup>
How worried were you about a family member getting sick from COVID-19?				
Extremely worried	36.9 (468)	36.7 (234)	37.1 (234)	0.9974
Somewhat worried	36.5 (463)	36.5 (233)	36.5 (230)	—
A little worried	20.2 (256)	20.2 (129)	20.1 (127)	—
Not at all	36.9 (468)	6.6 (42)	6.3 (40)	—
The MOST distressing thing for you during the COVID-19 pandemic				
Worrying about a family member's health	42.6 (472)	40.7 (224)	44.5 (248)	0.6081 <sup>c</sup>
Getting infected with COVID-19	32.6 (361)	34.0 (187)	31.2 (174)	—
Having my IBD flare	11.0 (122)	12.0 (66)	10.1 (56)	—
Worrying about finances	10.6 (117)	10.2 (56)	11.0 (61)	—
Inability to see my doctor	3.2 (35)	3.1 (17)	3.2 (18)	—
If you were on IBD therapy, did you adjust your own IBD meds on your own? <sup>c</sup> % (n) Yes	10.8 (93)	8.23 (34)	13.2 (59)	<b>0.0208</b>
Did your doctor adjust your IBD meds? <sup>c</sup> % (n) Yes	12.6 (108)	12.7 (53)	12.4 (55)	0.9181
Do you have a mental health diagnosis? (depression, anxiety disorder, bipolar disorder, schizophrenia, or PTSD) % (n) Yes	21.3 (275)	22.7 (147)	19.8 (128)	0.2213
If you have a mental health diagnosis, are you taking medications for your mental health? % (n) Yes	78.0 (213)	82.2 (120)	73.2 (93)	0.0804
Did you feel you needed help from a mental health professional during the COVID-19 pandemic? % (n) Yes	12.1 (155)	13.1 (84)	11.0 (71)	0.2665
If you felt you needed help from a mental health professional, did you feel you had adequate access to a mental health professional during the COVID-19 pandemic? <sup>d</sup> % (n) Yes	54.6 (83)	48.2 (40)	62.3 (43)	0.1021
Percentage with elevated health anxiety score, % (n)	17.2 (223)	17.7 (115)	16.7 (108)	0.6590
Percentage with elevated stress score scale, % (n)	63.5 (823)	64.6 (419)	62.4 (404)	0.4533

Notes: Bold= Statistical significance at  $P \leq 0.05$ .

<sup>a</sup>Only people with children in childcare answered.

<sup>b</sup>Only answered if they had a job.

<sup>c</sup>Percentage of patients who are on IBD medications (901 patients on IBD therapy, 424 CD people on IBD therapy, and 455 UC people on IBD therapy).

<sup>d</sup>Denominator was people who felt they needed help from a mental health professional.

<sup>\*</sup>P value = *t* test for continuous variables, Fisher's exact test for categorical variables.

<sup>\*\*</sup>P value = Chi-square test.

## Discussion

In this population-based sample of adults with IBD during the second wave of the COVID-19 pandemic, one in five reported a pre-existing mental health diagnosis, and approximately three-quarters of respondents reported increased stress. For most, stress was focused on family well-being increased during the pandemic, with increased stress also evident regarding their work, financial stability, and their IBD. While almost half acknowledged more stress about accessing their health care provider during the pandemic, close to two-thirds felt they were able to access their health care provider as needed, although only half felt they had good access specifically to their gastroenterologist. While these findings would suggest there was still a significant minority who did not have the needed access for their health care concerns, compared with information we had available pre-COVID regarding access, there may have been an improvement. That is, in a study accessing participants from this registry undertaken in 2017, 42% reported having good access to their gastroenterologist by telephone when needed,<sup>16</sup> whereas 56% reported good access at this point in the pandemic. Physician access could have improved, as there was increased availability of telemedicine options fairly early in the pandemic in this jurisdiction. However,

nearly half of respondents with mental health issues felt they did not have adequate access to a mental health professional.

It is well established that persons with IBD have significantly higher rates of depression and anxiety than the general population and that mental health symptoms exacerbate disease symptoms and impair quality of life.<sup>17,18</sup> A study of older adults with IBD ( $\geq 65$  years old) found 22.6% met the criteria for major depression, were more likely to be on corticosteroids and had worse medication adherence, compared to those without depression.<sup>19</sup> In our study, we found that older age was associated with a decreased likelihood of health anxiety or of elevated stress, though this was only statistically significant on univariate analysis.

It is well known that older people are at increased risk of severe disease and death with COVID-19,<sup>20</sup> with one meta-analysis calculating a hazard ratio of 2.61 for mortality in older people.<sup>21</sup> Despite the publicity surrounding the risk of COVID-19 to the elderly as well as for those with underlying conditions, older people had decreased health anxiety and perceived stress in our study. Similarly, a Norwegian survey study found that persons with IBD (more than 95% on biologic therapy) who were less than 50 had more concerns about their treatment in the context of COVID-19 than those

**Table 4.** Univariable and multivariable predictors of elevated health anxiety (SHAI > 17).

	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Age (65+ vs. 17–64)	<b>0.69 (0.51–0.94)</b>	<b>0.63 (0.42–0.93)</b>
Disease duration (years)		
11–30 vs. 0–10	0.88 (0.59–1.32)	0.97 (0.63–1.48)
30+ vs. 0–10	0.68 (0.45–1.05)	0.85 (0.52–13.8)
IBD phenotype (CD vs. UC)	1.08 (0.81–1.43)	0.83 (0.60–1.17)
Immune-modifying therapy	<b>1.81 (1.36–2.39)</b>	<b>1.60 (1.15–2.22)</b>
Presence of GI symptoms	<b>2.97 (2.21–4.00)</b>	<b>2.88 (2.08–3.99)</b>
Working from home	1.06 (0.77–1.45)	0.88 (0.61–1.28)
Children at home	1.22 (0.89–1.66)	0.86 (0.59–1.25)
Less hours	1.01 (0.64–1.57)	0.70 (0.41–1.19)
Frontline worker	1.08 (0.69–1.68)	0.77 (0.46–1.29)

Notes: CD = Crohn's disease; GI = gastrointestinal; IMT = immune-modifying therapy; SHAI = Short health anxiety inventory; UC = Ulcerative colitis. N = 1,211 total observations used in the full model, SHAI > 17 (N = 204). Bold= significant at P < 0.05.

**Table 5.** Univariate and multivariable predictors of elevated perceived stress (PSS10 > 13).

	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Age (65+ vs. 17–64)	<b>0.59 (0.47–0.74)</b>	0.77 (0.57–1.03)
Disease duration (years)		
11–30 vs. 0–10	0.73 (0.52–1.04)	—
30+ vs. 0–10	<b>0.62 (0.43–0.89)</b>	—
Disease type (CD vs. UC)	1.10 (0.87–1.37)	0.92 (0.70–1.19)
Immune-modifying therapy (Yes vs. no)	<b>1.56 (1.24–1.97)</b>	—
GI symptoms (yes vs. no)	<b>2.38 (1.88–3.00)</b>	<b>2.37 (1.83–3.07)</b>
Working from home (yes vs. no)	<b>1.62 (1.25–2.10)</b>	<b>1.41 (1.03–1.92)</b>
Children at home (yes vs. no)	<b>1.64 (1.27–2.13)</b>	1.20 (0.87–1.66)
Less hours (yes vs. no)	<b>1.61 (1.11–2.34)</b>	1.23 (0.81–1.87)
Frontline worker (yes vs. no/unsure)	<b>2.24 (1.50–3.36)</b>	<b>1.94 (1.22–3.09)</b>
Disease duration (years)		
11–30 vs. 0–10—not on IMT	—	1.05 (0.64–1.70)
11–30 vs. 0–10—on IMT	—	<b>0.52 (0.29–0.93)</b>
30+ vs. 0–10—not on IMT	—	1.38 (0.83–2.30)
30+ vs. 0–10—on IMT	—	<b>0.45 (0.24–0.84)</b>

Notes: CD = Crohn's disease; GI = gastrointestinal; IMT = immune-modifying therapy; PSS = perceived stress scale; UC = ulcerative colitis. N = 1,211 total observations used in the full model, PSS10 > 13 (N = 774). Bold= significant at P < 0.05.

over 50.<sup>22</sup> A national Australian survey of individuals with IBD during the COVID-19 pandemic revealed younger age was associated with significant stress, anxiety, and/or depression.<sup>9</sup> It is known that mental health disorders decrease as people age.<sup>23</sup>

Nearly 40% of participants were on some form of immune-modifying therapy, and this was associated with increased odds of health anxiety and perceived stress. Being on immune-modifying therapy by definition means these people either have moderate-to-severe disease or have mild disease but have failed prior therapies. While one may think that this experience would lead to an increase in their resilience, persons on immune-modifying therapies may have perceived themselves to be at increased risk of contracting COVID-19, and been concerned that in needing more care, they might not have ready access to timely care.

Longer IBD disease duration was associated with decreased odds of perceived stress, including those on immune-modifying therapies. It is possible that the longer one has IBD, they develop resilience and coping mechanisms and are better able to handle the stress of COVID-19. It has been shown that increased resilience is associated with lower disease activity and improved quality-of-life,<sup>24</sup> as well as decreased rates of anxiety and depression.<sup>25</sup> Persons with IBD who have active disease can feel isolated, although they can still have good social support, comparable to people without IBD.<sup>26</sup>

Of the respondents who were on some form of IBD therapy, 10.8% adjusted therapy on their own, and 21.1% of respondents felt increased stress accessing their IBD medications. An observational survey in Italy during the COVID-19 pandemic revealed that 16.3% of respondents discontinued therapy on their own, while 37.4% delayed



therapy, mostly related to a fear of COVID-19.<sup>27</sup> It's unknown what led to these autonomous changes, perhaps the thought that decreasing one's own therapy would lessen one's risk of contracting COVID-19, though 20.3% of respondents felt increased stress about accessing their IBD medications. Unfortunately, we do not know what the base rates in our population were for self-adjusting therapy in a non-pandemic era.

A large study assessing healthcare claims data in the United States showed a reduction in colonoscopies and initiation/switching of IBD therapies early on in the COVID-19 pandemic, while telehealth services use increased.<sup>3</sup> Whether a decrease in healthcare utilization early on in the pandemic led to the worsening of one's disease status is not yet known. This decrease in procedures, or perhaps the fear of not getting the care one should receive, could have led to increased anxiety or perceived stress. A small Dutch survey study ( $n = 63$ ), reported that lockdown-related social isolation and fear of COVID-19 were associated with clinical activity of CD.<sup>28</sup> Since high perceived stress is significantly associated with symptom flares,<sup>7</sup> it will be of interest to determine if participants in our study with high perceived stress ultimately did have increased disease activity.<sup>29</sup> In the future we will be studying our cohort's health care utilization including colonoscopies and their ultimate health IBD health outcomes.

Of course, people without IBD also experienced elevated health anxiety and stress during the pandemic. Some expect long-term mental health consequences throughout the population secondary to the pandemic, especially from prolonged lockdown measures and social isolation.<sup>30</sup> A Canadian survey of 3,000 people during the first wave of the pandemic revealed that 37.4% of respondents had worse mental health at the time of the survey compared with pre-pandemic, with 41.9% of respondents who quarantined reporting worsening mental health symptoms.<sup>31</sup> A meta-analysis revealed symptoms of psychological distress, depression, and anxiety were all found to be higher during the first wave of the COVID-19 pandemic.<sup>32</sup>

Our study has many strengths, including an excellent response rate (47.1%) of a population-based sample. The responses were during the second wave of the COVID-19 pandemic, before vaccines were available, and while key information about this novel virus was still being discovered. People in this region, similar to other regions and countries, experienced frequent government-mandated lockdowns and restrictions on public and private gatherings. Hence, these data reflect a specific, early time in the pandemic and highlight some of the needs of persons with IBD during a pandemic such as better access to their gastroenterologist and mental health professionals. Our study also has some limitations. Our cohort was older with a modestly higher proportion of women. The study design was cross-sectional, which does not allow for change comparisons from pre-pandemic levels of health anxiety and stress, or potential effect on IBD disease state. A major limitation is our study did not have a comparison group of adults without IBD to compare rates of elevated health anxiety and stress in the general population in the context of the pandemic. While most people, even those without IBD, had an increase in clinically significant mental health symptoms, we feel our results highlight the stressors and anxieties that people with IBD encountered during the pandemic, and this may help to identify areas to target in the future.

Persons with IBD are already at increased risk of mental health disorders compared with the general population. It is possible that increased resilience, and experience dealing with a chronic disease over years prepared some for the rigors of dealing with COVID-19. More research is needed to assess if heightened levels of stress or health anxiety lead to worsening disease activity, and further if the delay in health care aspects such as colonoscopies and surgeries or the perceived decreased access to health care professionals for some with IBD during strict lockdowns will have detrimentally impacted the disease course for persons with IBD. The importance of understanding the experiences of persons with IBD during the COVID-19 pandemic can guide the current response to ongoing needs, especially if the needs have increased overall for this patient population, in addition to considering changes in our approach to clinical care during future waves of the current or other pandemics.

### Supplementary data

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

### Author contributions

Seth R. Shaffer (study concept and design, analysis and interpretation of data; drafting of the manuscript; critical revision of the manuscript for important intellectual content; statistical analysis), Gia L. Jackson (acquisition of data), Sydney Chochinov (acquisition of data), Casanadra Dolovich (analysis and interpretation of data; critical revision of the manuscript for important intellectual content; statistical analysis; technical, or material support; study supervision), Lesley Graff (study concept and design; analysis and interpretation of data; critical revision of the manuscript for important intellectual content), Renee E.L. Gabalawy (analysis and interpretation of data; drafting of the manuscript; critical revision of the manuscript for important intellectual content), Souradet Shaw (study concept and design; acquisition of data; analysis and interpretation of data; critical revision of the manuscript for important intellectual content), Harminder Singh (analysis and interpretation of data; critical revision of the manuscript for important intellectual content; technical, or material support), and Charles N. Bernstein (acquisition of funding, study concept, and design; acquisition of data; analysis and interpretation of data; drafting of the manuscript; critical revision of the manuscript for important intellectual content; statistical analysis; technical, or material support; study supervision)

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### Conflict of interest statement

Dr. Shaffer has served on advisory boards or consulted with Takeda Canada, Janssen Canada, and Pfizer Canada. Dr. Bernstein has consulted to or served on advisory boards for Abbvie Canada, Amgen Canada, Bristol Myers Squibb Canada, JAMP Pharmaceuticals, Janssen Canada, Pfizer Canada, Sandoz Canada, Takeda, and has received

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## Data availability statement

The data underlying this article are available in the article and in its online supplementary material.

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