IBD Patients' Perception of Severe Acute Respiratory Syndrome Coronavirus 2 Pandemic and Satisfaction with Provided Healthcare: A Cross-Sectional Study

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ABSTRACT

Background: *Severe acute respiratory syndrome coronavirus 2 pandemic is affecting public health systems and mental health significantly. Patients with inflammatory bowel disease are witnessing vigorous organizational changes in inflammatory bowel disease centers and experiencing all psychosocial effects of the crisis. We conducted a single-center cross-sectional study in order to assess inflammatory bowel disease patients' concerns, behavior, and satisfaction with provided healthcare during severe acute respiratory syndrome coronavirus 2 pandemic.*

Methods: *All inflammatory bowel disease patients treated in our center from April 1 to June 1, 2020, were invited to fulfill an anonymous online questionnaire.*

Results: *A total of 132 participants have completed the questionnaire, 63.2% were female, 57.9% had Crohn's disease (CD) During the first wave of the pandemic, 74.2% of participants perceived themselves as a high-risk group for acquiring coronavirus disease 2019 only because they suffered from inflammatory bowel disease, and 66.2% thought inflammatory bowel disease medications make them more susceptible to coronavirus disease 2019. This especially concerned patients treated with biologics ($B = 2.068$, $P < .01$). Females were more stressed ($B = -1.451$, $P < .01$) and concerned ($B = -1.488$, $P < .01$) about the pandemic, and they also reported more potential benefits from professional psychological help ($B = -2.664$, $P = .02$). Six patients (5.3%) discontinued inflammatory bowel disease therapy on their own initiative. Seventy-eight (68.4%) patients were completely satisfied and 14 (12.3%) were partially satisfied with the quality of healthcare provided in our inflammatory bowel disease center.*

Conclusion: *Female inflammatory bowel disease patients tend to be more emotionally vulnerable during severe acute respiratory syndrome coronavirus 2 pandemic. Although psychological support should be continuously available to all inflammatory bowel disease patients, female gender may warrant special attention. Providing patients with adequate and early information during pandemic probably leads to better compliance and higher satisfaction.*

Keywords: *COVID-19, Crohn's disease, inflammatory bowel disease, psychological distress, quality of life, ulcerative colitis*

INTRODUCTION

A novel respiratory virus, named severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was first described in December 2019 in Wuhan, China. Coronavirus disease 2019 (COVID-19), caused by SARS-CoV-2, subsequently spread across the globe. After the World Health Organization declared COVID-19 pandemic, on March 11, 2020,[1] many countries introduced strict measures, colloquially called "lockdown."[2] Widespread use of social media and the internet, despite many advantages, also brought an overload of disinformation. These and other notable factors have a considerable effect on psychological, social, economic, and overall well-being of the world population.[3,4]

Far-reaching consequences of the pandemic are seen in physical and mental public health. In many countries, public health systems are collapsing under SARS-CoV-2 spread[5]: shortage of intensive care unit beds, lack of personal protective equipment, disruption to treatment services for non-communicable diseases, and postponing of screening are widely observed. Avoiding social contacts, school closure, cessation of nonessential productions, economy stagnation, and consequently higher unemployment rate lead to a higher burden of depression, anxiety, and psychological distress.[6,7] Specific group of the population seems to be at higher risk for developing these disorders,[5] for example, children,[8] healthcare

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workers,[7] patients with previously known psychiatric disorders,[9] and so on. Moreover, immunocompromised patients and patients with pre-existing comorbidities tend to have poorer clinical outcomes.[10]

Inflammatory bowel disease (IBD) is a relapse-remitting chronic condition that impacts patient's quality of life significantly. Depression and anxiety are commonly seen among IBD population.[11,12] They are not only consequences of the disease but also predictors for worse outcomes.[13,14]

At the beginning of COVID-19 outbreak, little was known about its impact on IBD population, and special concerns arose over different modalities of immunosuppressive therapy. Moreover, during the pandemic crisis, on March 22, an earthquake hit our capital city, Zagreb, causing not only additional stress to our citizens but also significant damages in our hospital. Therefore, our department underwent vigorous reorganization: remote check-ups, additional email addresses and telephone lines along with protective measures in the day-care unit facility for intravenous biologics were introduced. We also canceled all elective procedures and introduced two 14-day shifts. One-half of the personnel worked from home and the other half worked at the hospital, thus minimizing the possibility of infecting the entire ward. Online and printed brochures about IBD and COVID-19 were widely available as printed versions in our hospital and online at the official hospital website.

Main Points

- *Many people worldwide face with emotional disturbances due to coronavirus disease 19 pandemic and its consequences. In our survey, 42.1% of patients stated that pandemic and subsequent "lockdown" significantly reflected on their emotional and psychosocial well-being. The psychosocial vulnerability of inflammatory bowel disease (IBD) patients warrants implementation of emotional distress assessment during the pandemic.*
- *In our study, female patients reported higher level of stress and anxiety. Moreover, this group was more likely to state they could benefit from professional psychological help. Although psychological support should be continuously available to all IBD patients, female gender may warrant special attention.*
- *Providing patients with adequate and early information during pandemic (via brochures, webinars, popular articles) and facilitating IBD team accessibility (communication via social networks, emails, etc.) probably leads to better compliance and higher satisfaction.*

After introducing all aforementioned novelties, a cross-sectional study was conducted in order to assess (1) burden of emotional stress and levels of concern caused by COVID-19; (2) perceived risk of IBD medications during the pandemic; (3) health behavior and compliance with therapy; and (4) satisfaction with provided healthcare during SARS-CoV-2 pandemic. Furthermore, we aimed to detect patient's characteristics that were connected with greater risk of emotional disturbances in order to provide them with adequate psychological support.

MATERIALS AND METHODS

Participants

Sestre milosrdnice University Hospital Centre (UHC) is a tertiary IBD center caring for more than 1300 IBD patients. During the pandemic, due to organizational changes of public health system, 39 patients from another clinical hospital were redirected to our unit. Those were primarily patients treated with biologics. All IBD patients who had a medical appointment, remote control or diagnostic and therapeutic procedures in period from April 1 to June 1, 2020, were invited to fulfill an anonymous online questionnaire available at the official website of the UHC. Due to the nature of the survey (anonymous online survey without collecting IP addresses of respondents), the response rate cannot be determined. According to institutional policies, this type of study is automatically exempt from requiring ethics approval since there were no collected data that could reveal the participants' identity in any way.

Survey

A questionnaire was designed by a team of gastroenterologists and psychologists, and it consisted of several groups of questions: demographic characteristics, comorbidities and smoking status, type of IBD and medications including adherence to therapy, behavioral changes (e.g., alimentary changes, cessation of social contacts), patients' perception of risk of getting COVID-19 due to the nature of disease and medication they use, emotional status and employment condition, satisfaction with provided healthcare during the pandemic and use of telemedicine. Multiple-choice questions were predominant with an open-ended question at the end. The full list of survey questions is available as a supplementary file.

Statistical Analysis

Results from the survey are presented through descriptive analysis. Categorical variables were compared using

χ^2 test or Fisher's exact test. *P* values less than .05 in two-sided tests were considered statistically significant. Binominal logistic regression was used to determine factors related to emotional stress. Data analysis was performed with The Statistical Package for Social Sciences (SPSS) Version 20 (IBM Corp.; Armonk, NY, USA).

RESULTS

A total of 132 participants have completed the questionnaire. During the pandemic, 114 of them were treated in our hospital, while 18 were treated in other IBD centers so they were excluded from further analysis. Of the patients, 63.2% were females, 57.9% had CD, 35.1% had ulcerative colitis, and 7% stated that their IBD was unclassified. Almost all subjects were younger than 60 years, only 2 (1.8%) were 61 or older. Vast majority of participants had long-standing IBD diagnosis and only a few of them were newly diagnosed (70.2% had IBD for longer than 5 years, 21.1% between 2 and 5 years, and only 8.7% had a diagnosis of IBD for less than 2 years). In accordance with the long duration of disease, 72 (63.2%) patients were treated with biologics and only 11.1% of them were on combination therapy with immunosuppressants, mostly azathioprine. Only 15 patients (13.2%) reported comorbidities significantly associated with severe course of COVID-19 (hypertension, diabetes, chronic kidney disease, chronic obstructive lung disease, and malignant disease). Thirty-nine patients (34.2%) were smokers.

Perceived Risk for COVID-19 Acquisition and Discontinuation of Medication

During the first wave of the pandemic, 74.2% of participants perceived themselves as a high-risk group for acquiring COVID-19 only because they suffered from IBD, and 66.2% thought IBD medications make them more vulnerable during the pandemic. Patients treated with biologics were significantly more concerned with being infected than those treated with conventional therapy including corticosteroids ($\chi^2(1, N = 67) = 13.3$, $P < .01$). Of the patients, 6 (5.3%) discontinued IBD therapy on their own initiative due to the fear of acquiring the COVID-19 (2 patients ceased taking 5-aminosalicylates, 2 infliximab, 1 azathioprine, and 1 methotrexate). Interestingly, difference between smokers' and non-smokers' concerns about acquiring COVID-19 was not observed ($\chi^2(1, N = 97) = 1.2$, $P = .34$). Tendency of new COVID-19 cases decrement in our country was noticed around April 20, when measures of gradually "reopening" were announced. After this date, our IBD patients reported greater fear of acquiring COVID-19 compared to the period during complete lockdown, 54.9% versus 17.1% ($P = .04$).

Behavioral Changes

Half of the participants stated they reduce social contacts even with their household members. Most patients, 85.1%, did not change their diet, while 29.1% reported they started consuming dietary supplements such as multivitamins, probiotics, and "immune boosters." Women were more likely to change diet compared to men, 17.6% versus 2.4% ($P = .02$).

Emotional Status and Employment Condition

Of the patients, 42.1% stated that pandemic and subsequent "lockdown" reflected on their emotional and psychosocial well-being significantly. Some of them rated earthquake as an even greater stressor than SARS-CoV-2 pandemic (according to self-reporting in open-ending question at the end of the questionnaire). Only 39.6% of patients who reported emotional and psychological disturbances believed professional psychological help could benefit them. According to the answers, 13 out of 114 patients lost their job or were under high risk of becoming unemployed due to the "lockdown" and emerging economic crisis. Burden of emotional stress did not differ significantly between groups of patients with and without risk of job loss ($\chi^2(1, N = 97) = .152$, $P = .75$).

Potential factors contributing to higher emotional stress were subjected to a deeper analysis of logistic regression. The analysis was performed to assess the impact of certain demographic and disease-related factors on the likelihood of developing emotional stress, seeking psychological help, changing everyday behavior, and perceiving risk of disease acquiring. The binary dependent variables were coded as positive or negative answers to question:

1. Do you think that having IBD puts you at a greater risk for COVID-19?
2. Do you believe that your IBD medications make you more susceptible to COVID-19?
3. In the light of this pandemic, have you reduced contacts with household members?
4. Are you experiencing emotional and psychological difficulties due to your current situation (social distancing, self-isolation, working from home, etc.)?
5. Do you think you could benefit from professional psychological help during quarantine/self-isolation?

Subjects who answered "I don't know" were excluded from analyses. Independent variables included in analyses are shown in Table 1.

Only the regression model with psychological help as dependent variable was statistically significant $\chi^2(8, N = 84) = 16.54$, $P = .035$, explaining 26.5% of variance (Nagelkerke $R^2 = .265$). Significant predictors were gender and duration of IBD. Females reported more potential benefits from professional psychological help ($B = -2.664$, $P = .02$). The patients with disease duration longer than 5 years were more likely to benefit from psychological help compared to those with disease duration from 2 to 5 years ($B = -3.215$, $P = .02$). However, due to small number of patients in medium IBD duration group, these findings should be interpreted with caution. On the individual variable level, some gender differences were also observed for emotional stress ($B = -1.451$, $P < .01$) and for perceived risk for COVID-19 ($B = -1.488$, $P < .01$) as dependent variables, indicating that females were more stressed and concerned about the pandemic. Furthermore, the type of therapy was a significant predictor of attitude that IBD medications make the patient more susceptible to COVID-19 ($B = 2.068$, $P < .01$) indicating that patients with biological therapy perceive themselves more susceptible to COVID-19 infection.

Satisfaction with Provided Healthcare During Pandemic and Use of Telemedicine

Seventy-eight (68.4%) patients were completely satisfied and 14 (12.3%) were partially satisfied with the quality of healthcare provided in our IBD center. Eighty-one (71%) participants stated their IBD team provided them with sufficient information about the impact of SARS-CoV-2 on IBD during the pandemic. Considering communication during the pandemic, patients preferred phone calls (49.1%) and emails (31.6%), followed by special application/social networks (10.6%) and ambulatory visits (8.7%). Remote check-ups was considered as a convenient way of communication even after the resolution of SARS-CoV-2 pandemic in 58.8% of participants.

DISCUSSION

All introduced modifications in our everyday praxis were in accordance with government COVID-19 policy, and they did not differ significantly from other European countries.[15-18]

Similar to other studies,[19-21] substantial number of participants thought they were under higher risk of developing COVID-19 than the rest of the population, expressing special concerns about IBD medications. Although only

Table 1. Binary Logistic Regressions Full Model Results on Different Emotional, Psychological, and Behavioral Outcomes

	Greater Risk for COVID-19?		Medications Make You More Susceptible to COVID-19?		Reduced Contacts with Household Members?		Experiencing Emotional and Psychological Difficulties?		Benefit from Professional Psychological Help?	
Predictors	*B*	Exp (*B*)	*B*	Exp (*B*)	*B*	Exp (*B*)	*B*	Exp (*B*)	*B*	Exp (*B*)
Gender	−1.488**	0.226	−0.090	0.914	−0.205	0.815	−1.451**	0.234	−2.664*	0.070
Age	−0.615	0.541	−0.358	0.699	−0.616	0.540	−0.815	0.443	0.852	2.345
Smoking	0.731	2.078	−0.904	0.405	0.453	1.573	0.115	1.122	0.033	1.033
IBD type	0.342	1.408	1.005	2.731	0.315	1.370	−0.234	0.791	−0.931	0.394
IBD duration (long vs short)	−0.424	0.654	−0.249	0.780	−0.646	0.524	−0.150	0.861	−0.661	0.516
IBD duration (long vs medium)	−0.180	0.836	−0.635	0.530	−0.894	0.409	−2.297*	0.101	−3.215*	0.040
Comorbidity	−0.829	0.437	−0.595	0.552	−0.685	0.504	−0.197	0.821	−0.900	0.407
Therapy	0.071	1.073	2.068**	0.126	−0.548	0.578	−0.268	0.765	−0.505	0.603
Nagelkerke R^2	0.183		0.280		0.105		0.161		0.265	
χ^2	11.65		13.85		8.49		12.33		16.54*	

**$P < .01$; *$P < .05$; all DVs are coded 0 = "yes" and 1 = "no"; IVs are coded: gender (0 = males; 1 = females), age (0 = 18-40; 1 = over 41), smoking (0 = yes; 1 = no), IBD type (0 = Crohn's disease; 1 = ulcerative colitis), IBD duration (1 = less than 2 years; 2 = 2-5 years; 3 = more than 5 years; recoded to dummy variables comparing the group 3 with others), comorbidity (0 = no; 1 = yes), therapy (0 = all others; 1 = biological).
COVID-19, coronavirus disease 2019; IBD, inflammatory bowel disease.

11.1% of patients were on combined therapy with biologics and immunosuppressants, those taking biologics expressed greater fear of getting COVID-19 than those on conventional therapy, including other immunosuppressants and corticosteroids in doses over 20 mg. However, the proportion of patients who discontinued IBD medication on their own was similar to the IBD population examined in other studies.[19-21] Dietary changes and dietary supplements consumption were not frequently observed.

Albeit at the beginning of pandemic the media communicated the claims presented in certain scientific studies stating that smoking is a risk factor for developing severe COVID-19,[22] our smokers did not perceive themselves as group under higher risk compared to non-smokers. It is important to emphasize that smoking is still widespread[23] and socially acceptable in our country.

Another, probably culturally related, characteristic of our IBD population is the fact that they are reluctant to seek professional psychological help. In a previous survey conducted from October 10, 2019 to February 15, 2020, on 152 patients treated in our IBD unit, only 58.6% wanted a psychologist in IBD team (what does not imply they would seek their help). Now, we observed the same trend. Although 42.1% of participants reported emotional disturbances during COVID-19 pandemic, only 39.6% of them consider they could benefit from professional psychological help. These findings should encourage us to assess emotional distress among our IBD patients more often and reinforce destigmatization of psychological interventions. Performed logistic regression suggested that IBD women are more prone to seek psychological help during pandemic what is in accordance with the general population.[24]

Despite many difficulties medical systems worldwide have faced during COVID-19 pandemic, long-awaited digitalization and remote communication were easily introduced. Not only our organizational units easily shifted into "virtual world" but also patients' perception of remote check-ups changed significantly. Before COVID-19 pandemic, 80.3% of all IBD consultations in our unit were in-person, compared to only 18.5% during lockdown. Assessing our patients' preferences in a previously mentioned survey, 65.8% preferred in-person consultations before the pandemic, and during COVID-19 pandemic only 8.7%. Although age distribution of participants is significantly different in those 2 surveys, trend toward remote consultation is unquestionable.

High satisfaction of our patients may be attributed to the availability of IBD team during the pandemic and the consistent implementation of personal protective measures by the team. Early released informative brochures about COVID-19 and IBD with accurate scientific evidence probably contributed to it. Due to patients' suggestions and questionnaire results, our IBD team is now available on social networks as well.

It is important to emphasize that almost all participants in this online survey were younger than 60 years, probably due to low computer literacy among elderly people. Thus, concerns, medication compliance, and behavior among our IBD patients over 60 years old remain unknown. Moreover, at the time of the survey, medical appointments for patients on conventional therapy without signs of clinical relapse were more likely to be postponed either by patients or by IBD team members, explaining a small proportion of these patients recruited. Another potential source of bias is voluntary participation of respondents. Patients who were more concerned, more stressed, or those who would like "to make their point" were potentially more motivated to participate in this survey which may skew the results away from the opinion of the average patient. Vast majority of survey participants as well as subjects controlled in our IBD center (in-person or remote) during the pandemic were our chronic patients with long-term disease, while few of them were newly diagnosed. As the incidence of IBD certainly has not decreased during SARS-CoV-2 pandemic, imposed question is how many of them we miss to diagnose on time. This trend was well observed among oncology patients[25,26] and the consequences are yet to be seen.

In summary, this study provides an important insight into Croatian patients' perception of the current pandemic, their attitudes, and concerns–information crucial for developing high-quality healthcare for IBD patients.

Ethics Committee Approval: This type of study is exempt from requiring ethics approval since there were no collected data that could reveal the participants' identity in any way.

Informed Consent: No informed consent was needed because of the retrospective non-interventional study design.

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Interpretation – P.C., T.B.; Literature Search – D.O., S.P.; Writing Manuscript – P.C., T.B.; Critical Review – D.H., T.B.

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QUESTIONNAIRE

Sex

1. Female
2. Male

What is your age in years?

_____

Which hospital do you attend for your IBD care?

1. UHC Sisters of Mercy
2. UH Dubrava
3. Other (please specify)

Do you have any of the following diseases:

1. High blood pressure (hypertension)
2. Diabetes
3. Chronic obstructive pulmonary disease
4. Asthma
5. Chronic kidney disease
6. Malignant disease
7. Other autoimmune disease
8. Psychiatric disease

Do you smoke nicotine:

1. Yes
2. No

What type of IBD do you have:

1. Ulcerative colitis
2. Crohn's disease
3. Undetermined IBD
4. Pouchitis

How long do you have IBD:

1. Less than 2 years
2. Between 2-5 years
3. Longer than 5 years

What therapy do you currently take for your IBD?

1. Currently I don't take any medication for my IBD
2. Aminosalicilates (sulfasalazine, mesalazine)
3. Systemic corticosteroid (prednisone) in dose <20 mg per day
4. Systemic corticosteroid (prednisone) in dose >20 mg per day
5. Topical corticosteroid (budesonide)
6. Azathioprine
7. Methotrexate
8. Biologic therapy

If you are on biologics, please select one of the following medications:

1. Infliximab
2. Adalimumab
3. Golimumab
4. Vedolizumab
5. Ustekinumab
6. Tofacitinib

During COVID-19 pandemic, do you take regularly your IBD medication?

1. Yes
2. No

In the light of pandemic, have you reduced contacts with household members?

1. Yes
2. No
3. I don't know

Have you changed your diet due to fear of getting infected?

1. Yes
2. No
3. I don't know

Have you started to consume dietary supplements such as multivitamins, probiotics and "immune boosters"?

1. Yes
2. No

Are you satisfied with all the information you have got about impact of COVID-19 on your IBD and medication you take?

1. Yes
2. No
3. I don't know

Do you think that having IBD puts you in a greater risk for COVID-19?

1. Yes
2. No
3. I don't know

Have you noticed symptom worsening from the beginning of the pandemic?

1. Yes
2. No

Do you believe your IBD medications make you more susceptible to COVID-19?

1. Yes
2. No
3. I don't know

Are you experiencing emotional and psychological difficulties due to current situation (social distancing, self-isolation, working from home etc.)?

1. Yes
2. No
3. I don't know

Do you think you could benefit from professional psychological help during quarantine/self-isolation?

1. Yes
2. No
3. I don't know

Have you lost your job during COVID-19 pandemic?

1. Yes
2. No

Please rate your satisfaction with provided healthcare in our IBD center during COVID-19 pandemic:

1. Completely satisfied
2. Partially satisfied
3. Not satisfied

Do you consider that members of your IBD team gave you sufficient information about SARS-CoV-2 impact on IBD?

1. Yes
2. No
3. I don't know

What type of communication with IBD team do you prefer during pandemic?

1. Telephone
2. Email
3. In person
4. Via application
5. Via web portal
6. Via social networks

Do you think digital communication could replace direct contact with your IBD specialist in the future?

1. Yes
2. No
3. I don't know

Thank you for your participation. If you have any question, comment or observation please do not hesitate to share it:

_____