

Concerns and attitudes of patients with inflammatory bowel diseases during the COVID-19 pandemic

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Research Article

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Abstract

Background: The coronavirus disease 2019 (COVID-19) pandemic has changed inflammatory bowel disease (IBD) care. The use of telemedicine was quickly adopted, however the impact of COVID-19 on IBD patients' feelings and sense of security for their health has not been extensively evaluated.

Aims: Our aim was to assess patients' views and concerns regarding their IBD condition, compliance with treatment and preventive measures, accessibility to health services and sources of information they used during the coronavirus pandemic.

Methods: A questionnaire-based survey of patients with IBD (n=237) was conducted at a University and an NHS GI Units.

Results: Greek patients with IBD expressed high levels of fear of coronavirus infection, with more than 50% being afraid of dying as a result of COVID-19. Seven out of ten participants felt that their IBD medications increased risk of infection and this fear was significantly higher in patients on immunosuppression. Only 2% of patients discontinued treatment on their own, all of whom were receiving immunosuppression. More than 90% of participants reported staying home and washing their hands. Three quarters of patients had access to a doctor when needed and almost 50% used the electronic paperless prescription system. Participants were satisfied with the information they received regarding COVID-19. The main sources of information were media, internet and social networks, with only one third seeking guidance from their gastroenterologist.

Conclusions: The COVID-19 pandemic had a profound, negative effect on IBD patients' lives. COVID-19-related fears need to be actively addressed, particularly in IBD patients on immunosuppression, and relevant information should be continuously provided.

Introduction

The current pandemic of COrona Vlrus Disease 19 (COVID-19), which is caused by infection with the Severe Acute Respiratory Syndrome-CORonaVirus 2 (SARS-COV2), has, so far, affected 235 countries with its death toll exceeding 1,300,000 cases [1]. In response to this global health crisis, governments have implemented over the past months certain measures to contain the spread of the virus. Such actions included use of personal protective equipment and hygiene measures both by health care workers and the public, as well as various levels of social distancing, the latter been elevated to generalized or local lockdowns, when indicated by close epidemiological surveillance. Alongside those preventive measures, delivery of health care rapidly shifted to accommodate for the new challenges, given the exponentially growing number of infected cases. In this context, provision of services to chronically ill patients had to be redefined aiming to ensure continuity of care and promotion of safety [2] [3] [4].

Similar to other patient populations with chronic conditions, management of patients with inflammatory bowel diseases (IBD) had to adapt to the new situation that resulted from the pandemic. To facilitate clinical decisions, International IBD Societies [5] [6] published guidelines that covered regular follow-up, disease flares, endoscopy, treatment, hospital visits including infusion services, clinical trials, and implementation of telemedicine [7] [8]. Accordingly, IBD and GI-Units had to modify daily routines and practices, undertake specific measures to maintain continuity of care, minimize patients' visits to hospitals and ensure adequate communication between patients and healthcare providers. As countries went to general lockdown, main changes in IBD care included shifting to telemedicine and paperless electronic prescription services, home delivery of medications, isolation of infusion units and IBD clinics in COVID-free zones in hospitals, as well as cancelling non-urgent endoscopies and imaging [9] [10] [11] [12].

The aforementioned implemented changes in IBD care mostly focused on the most demanding, practical issues of disease monitoring and treatment, as those required a quick adaptation by both healthcare professionals and patients in the midst of the COVID-19 pandemic. Less attention, however, has been given to the effects that these sudden changes had on patients' general feelings, sense of security for their health status, and emotional stability. To address these issues, we undertook the present study which aimed to evaluate our patients' views and concerns regarding their IBD condition during the coronavirus pandemic. To accomplish our aim, we conducted a survey among IBD patients who are cared for in two GI-units in the Metropolitan Areas of Athens and Piraeus, Greece, via a questionnaire that was specifically designed for this purpose. Based on the patients' answers we report on the fears and concerns of IBD patients regarding risk from COVID-19, compliance to treatment, attitudes towards protective measures, and their access to and satisfaction from information during the pandemic.

Methods

IBD patients from two GI Units in Athens and Piraeus, Greece were asked to participate in our survey. The first GI Unit serves a large NHS hospital in Piraeus, the General Hospital of Nikaia "Agios Panteleimon", while the second is part of a University department at Sotiria Hospital, the main reference hospital for COVID-19 in Athens. Patients were asked to complete a questionnaire either in person (paper-based) or via email (online form). Recruitment occurred between 15th May 2020 and 15th June 2020. Of note, general lockdown measures in Greece were lifted on 4th May 2020. Prior to completing the questionnaires, patients were informed that their participation was voluntary and all answers were given anonymously. The aim of the survey was also explained.

A total of 370 patients were recruited, of which 146 were cared for at the General Hospital of Nikaia (NHS) and 224 at Sotiria Hospital (University). A proportion of patients (n=104) were enrolled in person, while the majority was contacted via email (n=266).

The questionnaire consisted of 39 questions, all of which had pre-defined multiple-choice answers (with the exception of age) (Supplementary file). The original questionnaire was in Greek. Questions covered

demographic data (age, sex, place of IBD care) and clinical IBD characteristics (disease type, medications), as well as other clinical aspects, such as presence of co-morbidities and smoking status. Questions addressed various aspects of COVID-19, including IBD patients' perceptions and fears towards the pandemic and in relation to their disease and medication; access to information and healthcare providers; habits and behaviors during and after the general lockdown; continuation of IBD care; compliance with general protective measures and contact with COVID-19 positive cases.

Data collection was done in Microsoft Excel. The software SPSSv23 was used for statistical analysis. Mean value and standard deviation (SD) are presented for the normally distributed variables, while total counts and percentages are presented for the categorical variables. The independent sample t-test and the non-parametric X^2 test were used for identification of statistically significant differences. A P -value=0.05 was used as threshold of statistical significance.

Results

Patient characteristics

A total of 370 IBD patients from two IBD centers were contacted by e-mail or during their hospital visits (infusion unit, outpatient appointment) and were asked to participate in our survey by answering the questionnaire. Response rate was 64% with a total of 237 patients participating in the survey. Mean age of all patients was 41.6 years, with equal distribution between male and female participants (49% vs. 51%). Sixty-eight percent (68%) of respondents had Crohn's disease (CD) and the rest ulcerative colitis (UC). For their IBD care, patients attended clinics at a University (53%) and an NHS hospital (47%) in the Metropolitan areas of Athens and Piraeus (Table 1). One hundred and four (n=104) patients from the NHS Hospital cohort completed the questionnaire in person, and another 8 from the same cohort answered via email. All participants from the University hospital cohort (n= 125) responded electronically.

At the time of the survey, 89% of patients were on immunosuppressive medications, and only 11% received non-immunosuppressive treatment with 5-aminosalicylates (5-ASAs). In the immunosuppressed group, the majority of patients received treatment with biologic agents (including tofacitinib) (76%), either as a monotherapy (64%) or in combination treatment (12%). Nine percent (9%) of patients were on immunomodulators alone, while corticosteroids were given in 6% of patients. Patients in the 5-ASA group were significantly older than those in the immunosuppressed group. Also, Crohn's disease was significantly more prevalent among immunosuppressed than non-immunosuppressed patients (Table 2).

According to WHO and CDC criteria for vulnerable and high-risk groups for COVID-19 [13] [14], a quarter of patients fulfilled one or more criteria, with 15% of participants being older than 60 years and 25% having at least one co-morbidity apart from IBD. Presence of co-morbidities was more frequent in the non-immunosuppressed group, however there was no significant difference compared to immunosuppressed patients ($p=0.054$). A third of respondents reported active smoking at the time of answering the questionnaire.

Perceptions and attitudes towards COVID-19 pandemic

We first asked our IBD patients whether they felt that their bowel condition increases their risk of SARS-COV2 infection. More than 40% of respondents felt a lot or moderate fear, while three quarters (76%) felt at least a little afraid of contacting the virus (Figure 1A). More than half of participants (59%) were afraid that they might die if they got infected by SARS-COV2, with 10% admitting of being very afraid. At the same time, one fourth of patients (26%) was not worried of dying as a result of COVID-19 (Figure 1C). Looking at a subgroup analysis for the different types of IBD medications, patients on aminosalicylates appeared equally afraid with those on immunosuppressive treatment both with respect to their fear of SARS-COV2 infection and the fear of dying if infected (Figures 1B, 1D).

Our next question concerned patients' perception with regards to their IBD treatment and the risk of COVID-19. A considerable proportion of respondents felt that IBD therapy increases their risk of SARS-COV2 infection (Figure 1E), with more than 70% being scared because of the IBD treatment they were receiving. Nevertheless, only 7% discontinued their therapy. Looking again at the subgroup analysis for the different types of IBD medications, patients on immunosuppression showed significantly higher levels of fear compared to those on non-immunosuppressive treatment ($p=0.001$). Almost half of the patients on 5-ASAs (48%) felt no fear with respect to their treatment and risk of coronavirus infection. On the contrary, for those on corticosteroids, biologics, immunomodulators and combination therapy no fear of treatment was expressed in 31%, 16%, 10% and 30% of patients respectively (Figure 1F). Looking at the levels (low, moderate, high) of fear felt among patients on immunosuppression, these did not differ among the different medication groups, with the majority of immunosuppressed patients expressing low and moderate levels of fear.

When we asked our patients whether they thought that the quality of their IBD care will be affected as a result of the COVID-19 pandemic, the majority replied that their healthcare will not be influenced. Nevertheless, a little more than a quarter of participants (27%) worried that the COVID-19 will have a negative impact on the quality of their healthcare. Interestingly, a small proportion of respondents (7%) felt that the pandemic might have a positive effect on the quality of care.

Behavior of IBD patients during COVID-19 pandemic

Compliance with preventive measures against COVID-19

Wanting to assess compliance with the preventive measures against COVID-19, we asked our patients whether they found it easy to comply with the specific actions that had been suggested and included 11 different aspects of their daily routines. According to their answers, the majority of participants showed very good compliance with the preventive measures. There was no difference between immunosuppressed and non-immunosuppressed patients (Table 2). From the eleven measures that

participants were asked about (overall median compliance 67%), they felt that it was easy to stay at home (93%) and to wash their hands (91%). They found it harder to use personal protective aids, such as masks, gloves and antiseptics (43% compliance), and this tendency was observed both for participants that stayed at home and those leaving the house to go to work (overall median compliance 71%). More than half of the respondents had access to masks (56%), gloves (66%) and antiseptics (64%), however 14% of patients were not able to get hold of these items.

A third of patients worked from home, while another third left home to go to work, and this proportion was similar for patients receiving immunosuppressive treatment and those on 5-ASAs (Table 2). The rest of participants were not employed at the time of the survey. From those that were not self-employed, a third worked from home following employer's encouragement, a third had to ask for permission to work from home and the rest had to go to their workplace.

During the lockdown, all patients on 5-ASAs and 89% of those on immunosuppressive medications left home to visit the hospital, have investigations done or go to the pharmacy. Following lockdown termination, 73% of patients visited the hospital or a diagnostic laboratory, despite admitting that they were afraid to do so. The fear did not differ between patients on immunosuppression and those on aminosalicylates.

Compliance with IBD treatment during the COVID-19 pandemic

Of the 237 IBD patients that participated in our survey, 16 (7%) discontinued treatment during the pandemic. Eleven patients (5%) stopped their medications after consulting their IBD physician, while 4 (2%) patients interrupted treatment on their own because of fear of COVID-19. One patient did not specify under what circumstances he discontinued treatment. No patient stopped therapy because of difficulty in obtaining medications or accessing the infusion unit.

All patients that discontinued treatment were among the immunosuppressed group. From the 4 patients that stopped treatment on their own, 2 discontinued azathioprine (one of them continued with mesalazine monotherapy), one stopped adalimumab injections and another one treatment with tofacitinib. The rest of the discontinuations (n=11) involved 4 patients on adalimumab, 3 on azathioprine, 1 on methotrexate, 2 on infliximab and 1 on combination therapy with ustekinumab, methotrexate and corticosteroids. All patients on 5-ASAs reported continuing their treatment on the pre-COVID-19 dosages. Of note, 5 out of the 11 patients that discontinued treatment following consultation with their gastroenterologist, were among the high-risk group, with one or more co-morbidities and/or age over 60 years. None of the 4 patients that discontinued treatment on their own was considered high risk. However, these 4 patients expressed moderate and high levels of fear regarding the risk of SARS-COV2 infection and IBD medications, while similar levels of fear were exhibited by 6 of the patients that consulted their doctor prior to treatment discontinuation.

We compared patients that continued and discontinued treatment with respect to their levels of fear of SARS-COV2 infection. Although not statistically significant, there was a trend of higher levels of fear among patients that discontinued treatment compared to those that continued, and that was observed both for fear of infection because of IBD and because of IBD treatment (Figure 2).

IBD care during the COVID-19 pandemic – Access to information and healthcare services

The majority of our IBD patients (76%) stated that they had access to a doctor when needed, during the coronavirus pandemic. Consultations were mainly done via telephone following modifications of IBD services to accommodate for patients' needs remotely. Almost half of the patients (46%) used the remote electronic prescription system that became available very soon after lockdown measures were implemented. The paperless e-prescription was equally used by the group of immunosuppressed and the non-immunosuppressed patients (Table 2). Only a small proportion of IBD outpatient appointments (OPA) were cancelled either by patients or physicians (11%). A total of 19% of participants had to cancel some form of investigation (laboratory, imaging, endoscopy). Almost all patients (90%) on intravenous biologics continued their infusions at their IBD center of care, with 8% having to schedule their infusions at a different venue. A third of patients on subcutaneous biologics chose to receive their prescriptions in person (31%), a third chose the remote electronic prescription system (35%) and another third to have their medications delivered for free at home (34%).

When we asked our patients whether they received adequate information regarding COVID-19 infection, the majority (90%) answered yes. Regarding the source of information, almost a third (31%) received information by their gastroenterologist, 8% by their GP or family physician, while the majority of respondents were informed by the media (39%), internet and social networks (38%) (Figure 3). The proportions of patients that were exclusively informed by their gastroenterologist was 24%, whereas 58% of participants were exclusively informed by the media, internet and social networks. This difference was observed both in the group of immunosuppressed and in the non-immunosuppressed patients, although not statistically significant ($p=0.702$).

Patients' satisfaction

We asked our patients regarding their satisfaction from their IBD management during the COVID-19 pandemic. The vast majority (98%) of respondents stated satisfied, with only 2% feeling dissatisfied. Most patients (95%) reported being at least moderately satisfied with their care (37% very satisfied, 85% satisfied), and only 3% expressed little satisfaction (Figure 4). Satisfaction levels were similar among immunosuppressed and non-immunosuppressed patients ($p=0.818$).

IBD patients and COVID-19 exposure

Of the total 237 respondents, only 4 (2%) IBD patients reported contact with a confirmed COVID-19 case. Of these, 10% presented with symptoms suggestive of coronavirus infection. One patient tested positive for the virus, but there was no need for hospital admission. More than half of participants (54%) reported being able to isolate themselves if required.

Discussion

In this survey of 237 Greek IBD patients we found that three quarters of our patients expressed fear of being infected with SARS-COV2, and more than half were afraid of dying as a result of COVID-19. Furthermore, seven out of ten participants thought that their IBD medications were the cause of their increased risk. In fact, the level of fear was significantly higher for those on immunosuppression, irrespective of the specific regimen, i.e. corticosteroids, immunomodulators, biologics. Our results are in line with those reported by an international survey undertaken by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA), with an overall fear of SARS-COV2 infection expressed by 85% of IBD patients and fear due to IBD treatment by 63% [15]. Looking at the subgroup of Greek patients that participated in the EFCCA survey, the corresponding numbers were 89% and 62% respectively [16]. The higher scores in terms of fear of infection might be explained by the different timing of the two surveys, as the EFCCA survey was done in the middle of the generalized lockdown, whereas ours took place at a later time, when the number of cases in Greece was lower.

Interestingly, despite their fear regarding increased risk of COVID-19 due to their IBD medications, the majority of patients remained compliant with their treatment. Only 2% stopped treatment on their own and 5% following consultation with their IBD physician. All patients that discontinued treatment were on immunosuppressive medications, and they tended to express higher levels of fear compared to patients that continued treatment. Interestingly, none of the patients on intravenous biologics stopped therapy and this could be explained by the more regular communication and direct contact with medical personnel during infusion visits. Our results are similar to the EFCCA survey and a study involving German IBD patients, as both reported treatment compliance rates during the pandemic as high as 96% [15] [17]. According to the updated results from the SECURE-IBD platform, there was no increased cumulative mortality and severe morbidity rates (ICU admission, need for ventilator) among SARS-COV2 infected patients on different IBD medications, with the notable exception of oral and parenteral corticosteroids [18]. Therefore, we should encourage our IBD patients to remain on their medications in order to avoid disease flares and decrease need for hospitalization and steroid administration. Actively reaching out and informing patients on immunosuppressive medications is imperative during the COVID-19 pandemic, as those patients are more prone to discontinue their therapies due to fear and anxiety regarding risk of SARS-COV2 infection.

In our study, we found that most of our IBD patients showed various degrees of compliance with preventive measures. Staying home and washing hands were adopted by the majority of participants

(>90%), while masks and antiseptics were only used by 43%, irrespective of whether patients stayed at home or went to work. Interestingly, only 14% of patients admitted not having access to personal protective equipment. Grunert et al. reported very strikingly similar figures regarding hand washing and leaving the house, combined with the “paradoxical” limited use of face masks and other protective equipment. The authors proposed that this could be a consequence of rapidly changing governmental COVID-19 protection policies [17]. At the time of our survey, Greek government had not yet implemented mandatory use of face masks and information regarding the issue was controversial. Therefore, patients might have been reluctant to abide to such measures.

From the early stages of COVID-19 pandemic, IBD care had to be redefined and changes were implemented to accommodate for patients’ needs remotely [2] [9] [19] [20]. Likewise, most of our consultations were done via telephone and patients could contact their IBD team members via phone, e-mail or text message, while specific information was also available on a dedicated closed group facebook page. Three quarters of our patients reported being able to access a doctor when needed, all patients on intravenous biologics continued their infusions, while almost half made use of the newly established remote electronic prescription system. A small proportion of patients had to cancel an appointment and a quarter some form of investigation. We feel that continuity of treatment and care was achieved, and this is reflected by the high levels of our patients’ satisfaction, with only 2% feeling dissatisfied. At the same time, the majority of participants did not worry that their IBD management will be compromised as a result of the COVID-19 pandemic, however about a quarter of patients felt apprehensive about the negative impact of COVID-19 on the quality of healthcare. A small proportion (7%) thought that the pandemic might serve to improve quality of health services. From a study looking at patients’ attitudes towards the new forms of delivery of care and specifically at telemedicine, authors conclude that telemedicine may not only serve as a contact means with patients during the pandemic, but it could facilitate communication among healthcare providers and patients in the future, particularly for patients living in smaller and remote areas [21]. When asked, 78.1% of patients attending a University Hospital infusion unit in London, found telephone appointments completely acceptable as a method of follow-up. From the same group of patients, 20.6% reported being concerned about access to IBD services over the next 3-6 months [22].

Ninety percent (90%) of our patients were satisfied with the information they received regarding COVID-19. In the EFCCA survey, 23% of patients were not happy with the information they obtained [15]. In a study from the UK, it was shown that a single clinical intervention providing information through an advice letter or contact by the IBD team, significantly reduced anxiety in IBD patients [23]. Higher levels of anxiety were independently associated with a lower level of knowledge about the clinical importance of COVID-19 in a group of Italian IBD patients [24]. Therefore, there is unquestionable need to offer continuous support and updated information to our IBD patients during the unprecedented times of the COVID-19 pandemic.

The high proportion of satisfaction with regards to adequacy of information expressed by our patients could be partly attributed to the fact that they are all cared for at tertiary IBD centers and most are

patients with complex diseases, highlighted by the large proportion of patients on biologics (76%). These patients may be more motivated in terms of their health and they are also in close contact with their IBD teams. In the study from the UK, authors found that IBD patients categorized in the moderate and high risk groups (as per British Society of Gastroenterology COVID-19- and IBD-related guidelines), felt that the information they received adequately addressed their concerns. In addition, patients on biologics were significantly more likely to have their anxieties discussed than those on other medications [23]. Evidently, we should keep in mind that patients with less severe or quiescent IBD are also in need of being actively informed and having their fears and anxieties addressed.

When we looked at the specific sources of information patients used, with interest we found that only one third of patients received advice from their gastroenterologist. The majority was exclusively informed by the media, internet and social networks. Similar trends were observed by the German group and the authors highlight the need to actively reach out to our patients and provide IBD-relevant information [17]. IBD organizations and patient associations offer patient-oriented information and resources for COVID-19 [25] [26]. Forty-five percent (45%) of British patients used Crohn's and Colitis UK to access information, while all patients from a study from the US requested frequent updates regarding COVID-19 from their gastroenterologist [21,22].

Our survey has limitations. It is based on patient groups that are cared for at tertiary IBD units in Athens and Piraeus and results might not be representable of other regions of Greece or of patient groups cared for by non-IBD specialists. The selective group of patients might also be more motivated towards answering the questionnaire and as already mentioned, possibly has more access to coronavirus-related information. Despite these limitations, involving patients from a University and an NHS Hospital, covering the Metropolitan Areas of Athens and Piraeus, increases the study population's diversity. Another limitation is that we did not involve a control group of healthy volunteers or of IBD patients not cared for in tertiary IBD centers.

In conclusion, our survey emphasizes the need to address IBD patients' fears and anxieties regarding SARS-COV2 infection and IBD treatments, especially for those individuals receiving immunosuppressive medications. As we are already moving into the second wave of the pandemic, the need for continuous provision of updated information, alongside support and continuity of care and treatment is even more vital. Emphasizing adherence and compliance to general protective measures against COVID-19 is also important to minimize risk of infection.

Declarations

Funding

No funding was sourced for this project.

Conflict of Interest

There are no conflicts to declare by all authors with respect to this project

Author Contributions

MT and GB conceived and designed the study; MP and SV performed the study and collected the data; MLC and GK analyzed and interpreted the data; MLC wrote the manuscript; GB, EZ and MT critically revised the manuscript for important intellectual content. All authors have given final approval of the version to be submitted.

Data availability statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

The Ethics Committee of the General Hospital of Nikaia and Piraeus "Agios Panteleimon" - General Hospital Dytikis Attikis Agia Varvara approves the commencement of the Non-Interventional Study of the effect of SARS-COV2 pandemic on the life of patients with Inflammatory Bowel Diseases (IBD). The Study will be conducted with no financial charges to the Hospital and following patients' consent.

References

- 1 Coronavirus disease (covid-19) pandemic, 2020, September 30. Available at: https://www.who.int/emergencies/diseases/novel-coronavirus-2019?gclid=CjwKCAjw2dD7BRASEiwAWCtCb-xG9ZgGioYCypwKFPMzEi5m6NoKRZ6aQmZ9RxhITKuvuDBXyq0WmhoC1lcQAvD_BwE.
- 2 Allocca M, Fiorino G, Furfaro Fet al. . Maintaining the Quality Standards of Care for Inflammatory Bowel Disease Patients During the COVID-19 Pandemic *Clin Gastroenterol Hepatol*. 2020;18:1882-1883.
- 3 Beran D, Aebischer Perone S, Castellsague Perolini Met al. . Beyond the virus: Ensuring continuity of care for people with diabetes during COVID-19 *Prim Care Diabetes*. 2020.
- 4 Minniti A, Maglione W, Pignataro F, Cappadona C, Caporali R, Del Papa N. Taking care of systemic sclerosis patients during COVID-19 pandemic: rethink the clinical activity *Clin Rheumatol*. 2020;39:2063-2065.
- 5 Allocca M, Fiorino G, Zallot Cet al. . Incidence and Patterns of COVID-19 Among Inflammatory Bowel Disease Patients From the Nancy and Milan Cohorts *Clin Gastroenterol Hepatol*. 2020;18:2134-2135.

- 6 Magro F, Rahier JF, Abeu Cet al. . Inflammatory bowel disease management during the COVID-19 outbreak: The 10 do's and don'ts from the ECCO-COVID Taskforce *J Crohns Colitis*. 2020.
- 7 Rubin DT, Abreu MT, Rai V, Siegel CA. Management of Patients With Crohn's Disease and Ulcerative Colitis During the Coronavirus Disease-2019 Pandemic: Results of an International Meeting *Gastroenterology*. 2020;159:6-13.e16.
- 8 Kennedy NA, Jones GR, Lamb CA et al. . British Society of Gastroenterology guidance for management of inflammatory bowel disease during the COVID-19 pandemic *Gut*. 2020;69:984-990.
- 9 Bamias G, Lagou S, Gizis Met al. . The Greek Response to COVID-19: A True Success Story from an IBD Perspective *Inflamm Bowel Dis*. 2020;26:1144-1148.
- 10 Foteinogiannopoulou K, Orfanoudaki E, Koutroubakis IE. Keeping on the High Quality of Health Care in Greek Inflammatory Bowel Disease Patients in the SARS-CoV-2 Era *Clin Gastroenterol Hepatol*. 2020;18:2380-2381.
- 11 Furfaro F, Vuitton L, Fiorino Get al. . SFED recommendations for IBD endoscopy during COVID-19 pandemic: Italian and French experience *Nature Reviews Gastroenterology & Hepatology*. 2020;17:507-516.
- 12 Scaldaferri F, Pugliese D, Privitera Get al. . Impact of COVID-19 pandemic on the daily management of biotechnological therapy in inflammatory bowel disease patients: Reorganisational response in a high-volume Italian inflammatory bowel disease centre *United European Gastroenterol J*. 2020;8:775-781.
- 13 Organization WH. Covid-19: Vulnerable and high risk groups. 2020.
- 14 People at increased risk, 2020, September 11. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.
- 15 D'Amico F, Rahier JF, Leone S, Peyrin-Biroulet L, Danese S. Views of patients with inflammatory bowel disease on the COVID-19 pandemic: a global survey *Lancet Gastroenterol Hepatol*. 2020;5:631-632.
- 16 Covid-19 IBD patients' perception, 2020, May 16. Available at: http://www.crohnhellas.gr/COVID-19/2020%20Survey%20Results%20Covid_EFCCA%20-%20Greece%20.pdf.
- 17 Grunert PC, Reuken PA, Stallhofer J, Teich N, Stallmach A. Inflammatory Bowel Disease in the COVID-19 Pandemic - the Patients' Perspective *J Crohns Colitis*. 2020.
- 18 Brenner EJ, Ungaro RC, Geary RB et al. . Corticosteroids, But Not TNF Antagonists, Are Associated With Adverse COVID-19 Outcomes in Patients With Inflammatory Bowel Diseases: Results From an International Registry *Gastroenterology*. 2020;159:481-491.e483.

- 19 Fiorino G, Allocca M, Furfaro Fet al. . Inflammatory Bowel Disease Care in the COVID-19 Pandemic Era: The Humanitas, Milan, Experience *J Crohns Colitis*. 2020;14:1330-1333.
- 20 Lees CW, Regueiro M, Mahadevan U, International Organization for the Study of Inflammatory Bowel D. Innovation in Inflammatory Bowel Disease Care During the COVID-19 Pandemic: Results of a Global Telemedicine Survey by the International Organization for the Study of Inflammatory Bowel Disease *Gastroenterology*. 2020;159:805-808.e801.
- 21 Hernandez Benabe S, Langshaw AH. IBD in the Times of COVID-19 *Inflamm Bowel Dis*. 2020;26:e92.
- 22 Clough JN, Hill KL, Duff Aet al. . Managing an IBD Infusion Unit During the COVID-19 Pandemic: Service Modifications and the Patient Perspective *Inflamm Bowel Dis*. 2020;26:e125-e126.
- 23 Mir N, Cheesbrough J, Troth Tet al. . COVID-19-related health anxieties and impact of specific interventions in patients with inflammatory bowel disease in the UK *Frontline Gastroenterol*. 2020:flgastro-2020-101633.
- 24 Spagnuolo R, Larussa T, Iannelli Cet al. . COVID-19 and Inflammatory Bowel Disease: Patient Knowledge and Perceptions in a Single Center Survey *Medicina (Kaunas)*. 2020;56.
- 25 Associations EFoCsaUC. COVID-19. 2020.
- 26 Updates Covid-19, 2020, September 21. Available at:
<http://www.crohnhellas.gr/category/%ce%bd%ce%ad%ce%b1/updates-covid-19/>.

Tables

Table 1: Demographic and clinical characteristics of IBD patients participating in our survey

Responders (n, %)	237 (64%)
Gender	
Female (n, %)	120 (51%)
IBD Diagnosis (n, %)	
Ulcerative Colitis (UC)	75 (32%)
Crohn's disease (CD)	160 (68%)
Age (years - mean, SD)	41.6 (13.6)
Age under 60 (n, %)	201 (85%)
IBD Therapy (n, %)	
Biologics, Tofacitinib (monotherapy)	151 (64%)
Immunomodulators (monotherapy)	21 (9%)
Corticosteroids (CS)	14 (6%)
5-ASA (monotherapy)	27 (11%)
Combination therapy	
Biologic – IM	29 (12%)
Smoking status	
Yes (n, %)	79 (33%)
Presence of co-morbidities (³ 1) (n, %)	60 (25%)
Place of IBD care (n, %)	
University hospital	125 (53%)
NHS hospital	112 (47%)

Table 2: Survey outcomes for immunosuppressed vs non-immunosuppressed patients

	Immunosuppressed (n=210)	Non-immunosuppressed (n=27)	<i>p</i> value
Patients' characteristics			
Age, years [mean (SD)]	40.9 (13.4)	46.7 (14.6)	0.041
IBD type [CD (%)]	151 (71.9)	8 (29.6)	<0.001
Comorbidities [yes (%)]	49 (23.6)	11 (40.7)	0.054
Smoking [yes (%)]	69 (32.9)	10 (37)	0.665
Place of IBD care [University/NHS (%)]	110/100 (52.4/47.6)	15/12 (55.6/44.4)	0.756
Patients' perceptions and fears			
Fear of SARS-COV2 infection because of IBD [mean score (SD)]	2.6 (0.98)	2.7 (1.18)	0.634
Fear of death if infected by SARS-COV2 [mean score (SD)]	3 (1)	2.9 (0.99)	0.687
Fear of SARS-COV2 infection because of IBD treatment [mean score (SD)]	2.5 (0.98)	3.3 (1.01)	0.001
Afraid that quality of healthcare will be affected by COVID-19 pandemic [yes (%)]	56 (26.7)	8 (29.6)	0.744
Afraid to visit hospital / diagnostic lab after the lockdown [yes (%)]	157 (74.8)	17 (63)	0.191
Patients' management			
IBD Treatment discontinuation [yes (%)]	15 (7.1)	0	0.137
Compliance with preventive measures [mean (SD)]	7.3 (2.9)	7.1 (3)	0.692
Use of remote prescription system [yes (%)]	97 (46.2)	13 (48.1)	0.848
During the lockdown, patient left home to:			
Go to work. [yes (%)]	66 (31.4)	8 (29.6)	0.849
Go to hospital / have investigations / pharmacy. [yes (%)]	188 (88.6)	27 (100)	0.077
Cancellation of outpatient appointment [yes (%)]	22 (10.5)	4 (14.8)	0.497
Cancellation / Postponement of laboratory / radiological / endoscopic investigations [yes (%)]	40 (19)	5 (18.5)	0.947
Handling of medical needs by	105 (50)	15 (56.7)	0.587

gastroenterologist [remotely (%)]			
Patients' satisfaction by IBD management [mean score (SD)]	1.8 (0.88)	1.9 (0.8)	0.818
Patient received adequate information for COVID-19. [yes (%)]	188 (89.5)	25 (92.6)	0.619
Patient received information exclusively by			0.702
Gastroenterologist [n (%)]	52 (24.8)	6 (22.2)	
Family physician / GP [n (%)]	9 (4.3)	2 (7.4)	
Media / Internet / Social networks [n (%)]	118 (56.2)	19 (70.4)	
Access to physician / GP if needed [yes (%)]	160 (76.2)	21 (77.8)	0.855

Figures

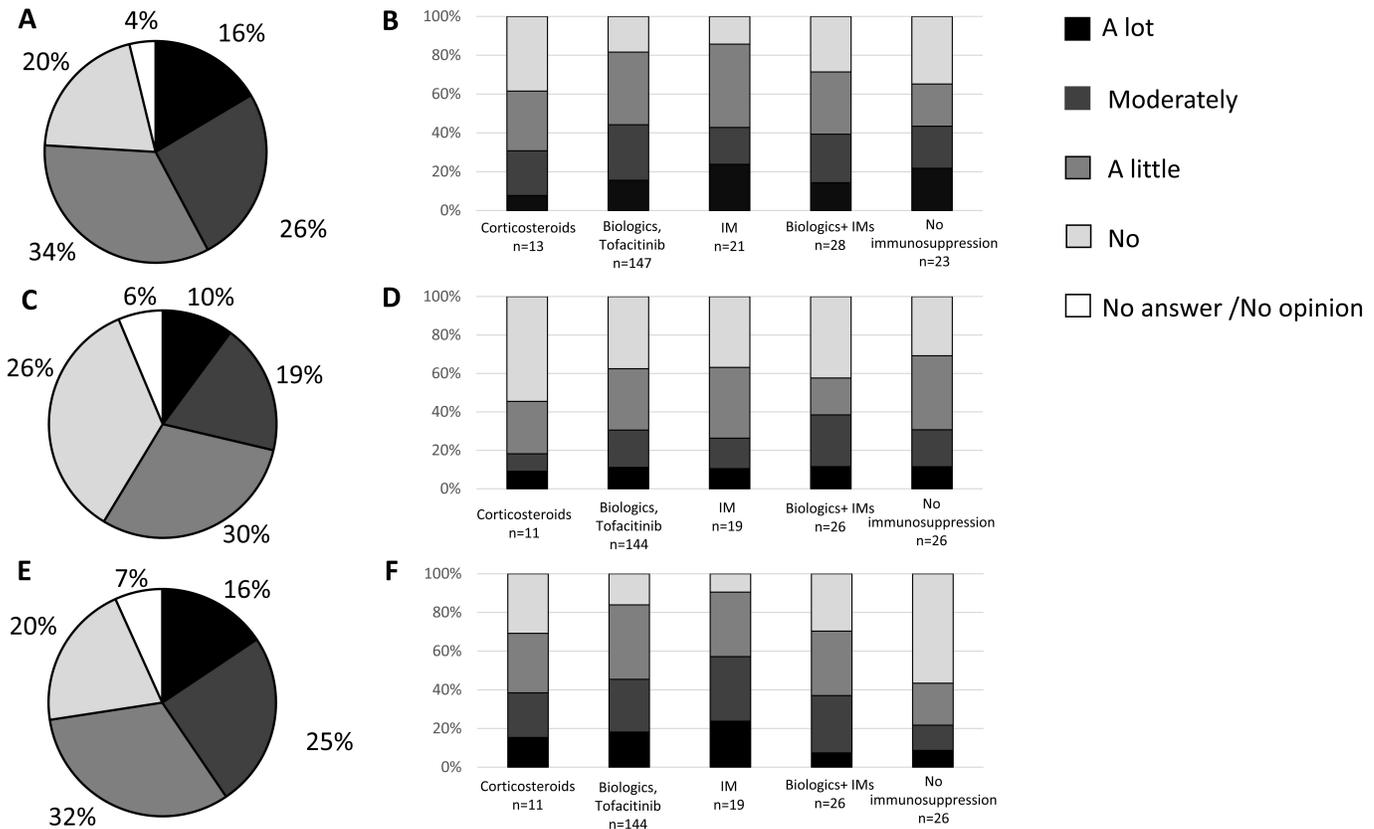


Figure 1

A) Responses to question “Are you afraid that you are at risk of getting more easily infected because of your IBD?” - Pie diagram showing percentage of patients that feared that their IBD increases risk of SARS-COV2 infection. B) Subgroup analysis of patients’ fear of SARS-COV2 infection because of IBD with respect to different types of IBD medications. C) Responses to question “Are you afraid that if you get infected you might die?” - Pie diagram showing percentage of patients that feared they might die in case

of SARS-COV2 infection. D) Subgroup analysis of patients' fear of death in case of SARS-COV2 infection with respect to different types of IBD medications. E) Responses to question "Are you afraid that you are at risk of getting more easily infected because of your IBD treatment?" - Pie diagram showing percentage of patients that feared their IBD treatment increases their risk of SARS-COV2 infection. F) Subgroup analysis of patients' fear of SARS-COV2 infection because of IBD treatment with respect to different types of IBD medications. CS: Corticosteroids; IM: Immunomodulators; No immunosuppression=5-aminosalicylates

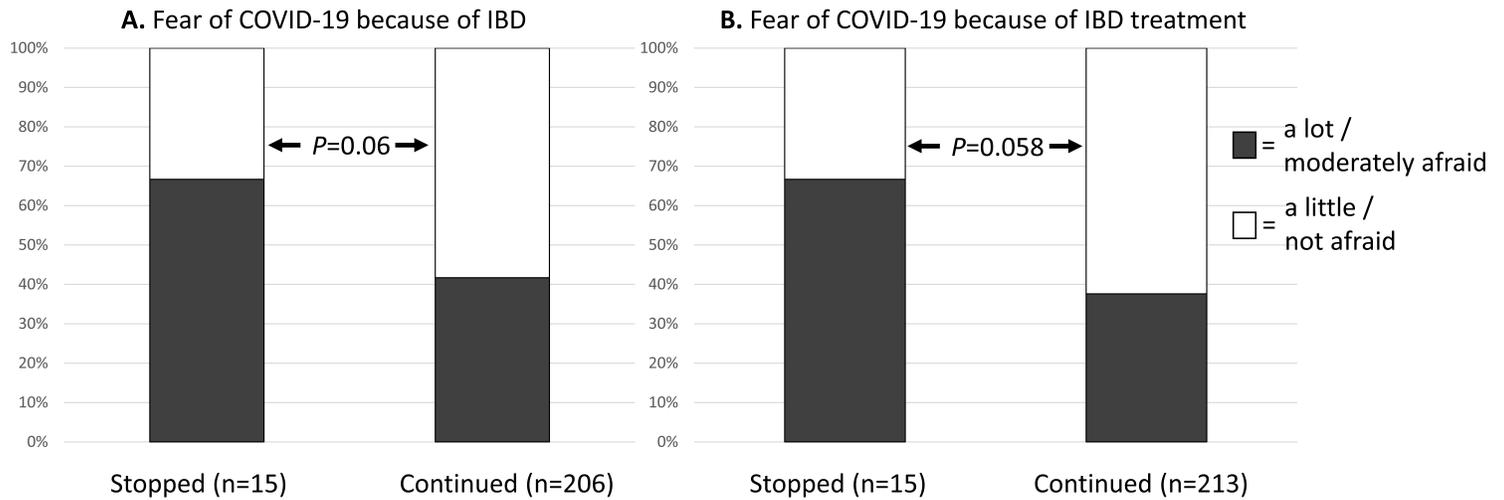


Figure 2

IBD treatment discontinuation / continuation with respect to levels of fear of COVID-19 A) because of IBD and B) because of IBD treatment

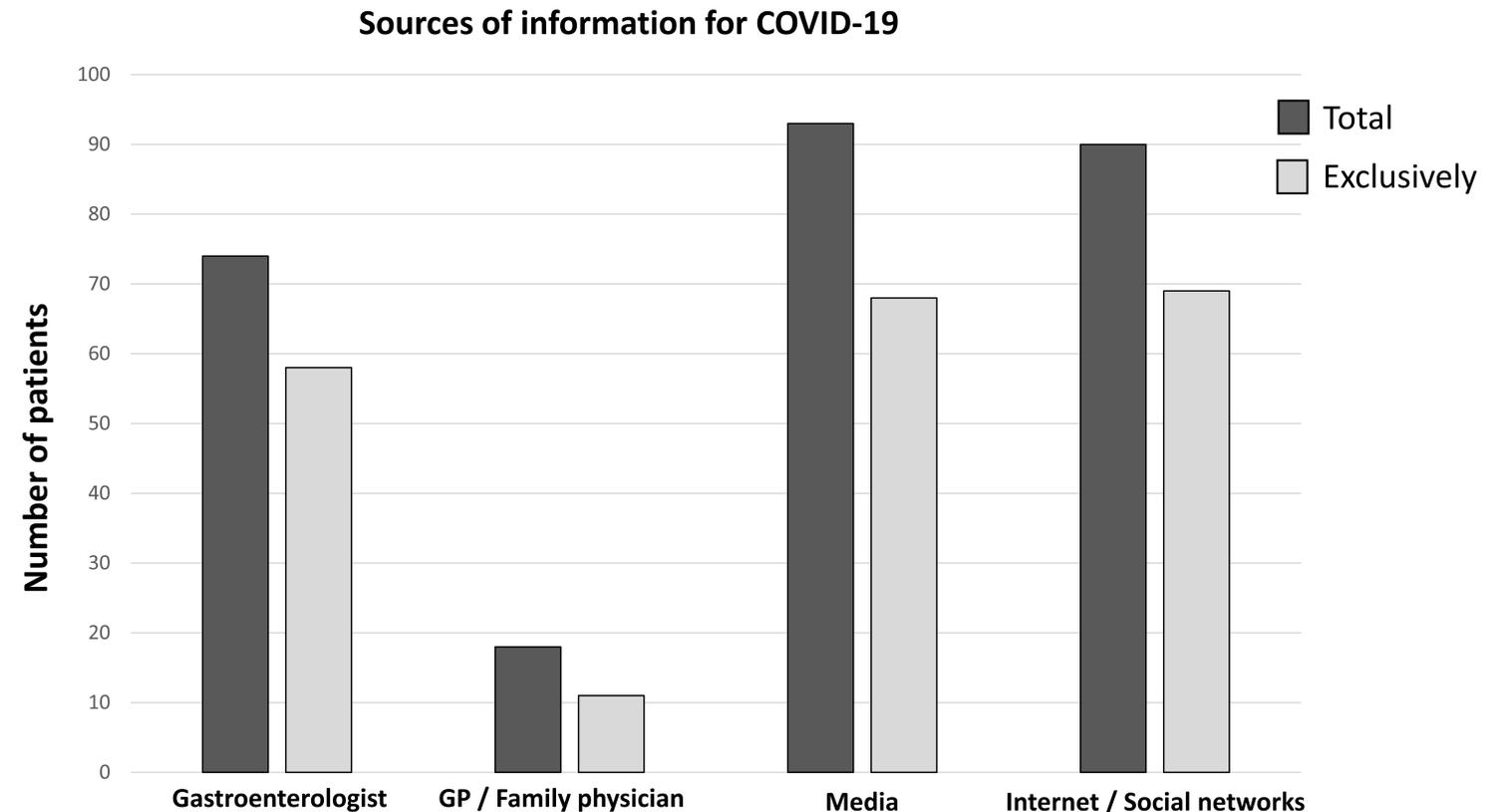


Figure 3

Sources of information for COVID-19 that patients used.

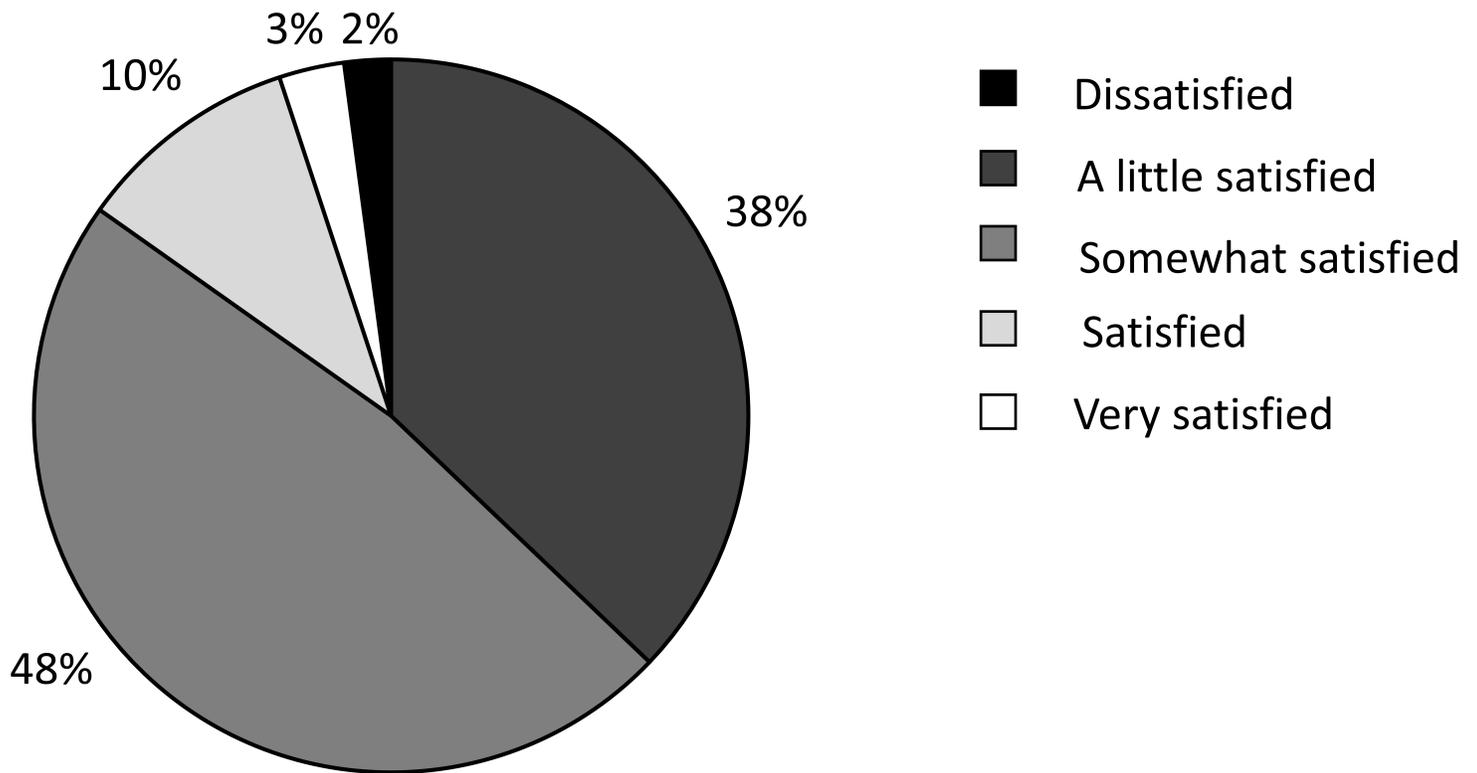


Figure 4

Pie diagram showing patients' satisfaction from their IBD management during the COVID-19 pandemic.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryfileStudyQuestionnaire.doc](#)