

Views of patients with inflammatory bowel disease on the COVID-19 pandemic: a global survey



Patients with chronic diseases have experienced substantial changes to the routine management of their conditions during the coronavirus disease 2019 (COVID-19) pandemic.^{1,2} Although insights into the management of patients with inflammatory bowel disease (IBD) during the outbreak have been described,³ little attention has been paid to the patients' point of view. Therefore, we did an anonymous web survey with the support of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) between March 30 and April 16, 2020, to investigate the concerns, fears, and behaviours of patients with IBD during the early phase of the COVID-19 pandemic.

The questionnaire was initially developed in English through the cooperation of IBD specialists and patient association representatives, focusing on the most frequent questions asked by patients during daily clinical practice. Subsequently, the questionnaire was translated into ten languages (Italian, Dutch, French, Spanish, Greek, Polish, Portuguese, Croatian, Bulgarian, and Slovenian) by volunteer native speakers. Patients with IBD were invited to participate in the survey via the EFCCA. We had responses from 3815 participants from 51 countries worldwide (appendix). The most represented region was Europe (32 [63%] of the 51 countries), followed by the Americas (nine [18%]), Asia (five [10%]), Australasia (three [6%]), and Africa (two [4%]). The mean age of the patients was 40.7 years (SD 12.8); most were women (2743 [72%] of 3815 respondents). More than half of the respondents had Crohn's disease (2211 [58%]), the remainder had ulcerative colitis (1528 [40%]) or indeterminate colitis (76 [2%]). Most respondents feared contracting COVID-19 (3242 [85%] of 3815 respondents) or infecting other people (3330 [87%]). Just under a third of patients believed that IBD predisposed them to an increased risk of COVID-19 (1150 [30%] of 3814 respondents), and nearly two-thirds of respondents stated that immunosuppressive drugs were associated with a higher risk of infection (2427 [64%] of 3815). In addition, most patients were concerned about contact with other people (3237 [85%] of 3815 respondents) and were afraid of travelling (3315 [87%] of 3814) and attending their hospital for follow-up consultations (2831 [74%] of

3814). Despite these worries, most patients (3373 [88%] of 3813 respondents) did not want to discontinue IBD medications during the pandemic and almost all (3670 [96%] of 3813 respondents) had not stopped taking their IBD medications on their own initiative. Importantly, about half of respondents reported receiving COVID-19 information (923 [44%] of 2116 respondents) or specific recommendations (1133 [52%] of 2172) from doctors to prevent infection. About a quarter of participants receiving recommendations were not satisfied with them (300 [23%] of 1304 respondents), but most patients (1184 [60%] of 1991) would have preferred to receive more recommendations regarding COVID-19 from their physician.

Most respondents reported reducing travel (3130 [96%] of 3256 respondents), modifying daily habits (3724 [98%] of 3814), and using protective aids (3183 [83%] of 3814) during daily life. The most adopted precautions were use of disinfectants (3074 [97%] of 3183 respondents), masks (2134 [67%]), and gloves (2015 [63%]). 1965 patients responded to questions regarding what factors helped to relieve their concerns and fears about COVID-19; patient associations (1601 [81%]) and relatives (1033 [53%]) were the most reassuring. By contrast—and worryingly—only a small proportion of people (218 [11%]) found relief from their fears and concerns about COVID-19 after a medical consultation.

The results of this survey highlight that a gap between doctors and patients still exists. There is an urgent need to improve physician–patient communication and to provide clear and specific recommendations in a period of substantial confusion for people with chronic diseases. The European Crohn's and Colitis Organisation, the British Society of Gastroenterology, and the International Organization for the Study of Inflammatory Bowel Diseases have responded to this request, providing practical guidelines for the management of patients with IBD during the pandemic, focusing not only on drug treatment but also on advice for daily life (eg, social distancing, use of masks, and travel avoidance).^{4–6} In patients with IBD who do not have symptoms suggestive of COVID-19,

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immunosuppressive and biological drugs should not be discontinued as a preventive strategy, since there is no evidence to date to suggest that there is an increased risk of SARS-CoV-2 infection with these therapies.⁴⁻⁶ In addition, patients are recommended to stay at home, avoid travel, respect the rules of social distancing (at least 1 m between one person and another), pay close attention to hand hygiene, and use protective masks outside the home.⁴⁻⁶ In this context, patient associations are a key link between doctors and patients and should be increasingly involved in patient management. Close cooperation could allow greater patient compliance with the recommendations of health-care providers and could also help to establish long-lasting, trusting relationships.

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