

Original Article



The COVID-19 Pandemic: Fears and Overprotection in Pediatric Patients with Inflammatory Bowel Disease and Their Families

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Conflict of Interest

AS reports consulting fees from Abbvie, Amgen, Astellas, Biogen, Celltrion, Consal, CSL Behring, Galapagos, Gilead, Institut Allergosan, Janssen, MSD, Norgine, Pfizer Pharma, Roche, Shire, Summit Therapeutics, and Takeda, lecture fees and travel support from Abbvie, Astellas, Celltrion, Falk Foundation, Ferring, Janssen, MSD, Recordati Pharma, and Takeda, and research support from Abbvie, outside the submitted work.

ABSTRACT

Purpose: The coronavirus disease 2019 (COVID-19) pandemic has influenced the lives of people worldwide. Little is known about the effects of the COVID-19 pandemic on the behavior and fears of pediatric patients with inflammatory bowel disease (IBD) and their families. We conducted a survey to determine the COVID-19 exposure, related perceptions, and information sources; medication compliance; and patients' and parents' behaviors, fears, and physician contact.

Methods: An anonymous cross-sectional survey of pediatric patients with IBD and their parents at one pediatric gastroenterology unit of a university medical center was performed.

Results: A total of 46 pediatric patients with IBD and 44 parents completed the survey. Parents of pediatric patients with IBD had high fear of their children becoming infected with severe acute respiratory syndrome coronavirus 2. They perceived schools as the most hazardous environment, whereas the children did not. Half the pediatric patients with IBD feared infection. Patients and parents felt sufficiently informed about COVID-19. The primary source of guidance for pediatric patients was their parents (43%), followed by television and social media, whereas the parents mainly consulted internet news websites (52.2%), television, and public health institutes. Pediatric patients with IBD adhered to their prescribed medication. They also showed cautious behavior by enhancing hand hygiene (84%) and leaving the house less frequently than before. However, in-person medical visits remained favored over video consultations.

Conclusion: Although parents expressed overprotective concerns, both parents and pediatric patients with IBD are coping well with the COVID-19 pandemic. IBD-relevant information should be actively conveyed.

Keywords: Inflammatory bowel disease; Children; Adolescents; Coronavirus disease 2019; Behavior

INTRODUCTION

Infection with the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes coronavirus disease 2019 (COVID-19), has become a global pandemic. Common symptoms of COVID-19 include fever, cough, shortness of breath, fatigue, loss of smell,

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and taste [1,2]. Older, immunocompromised people and those with cardiac or pulmonary comorbidities are at higher risk of complications and even lethal disease [1,3,4].

Pediatric patients with inflammatory bowel disease (IBD) are an exceptional population: on the one hand, children appear to have milder courses of COVID-19 [5]; on the other hand, people with comorbidities and immunosuppression, such as those with IBD, have been indicated in the media to be a high-risk population in the COVID-19 pandemic.

Emerging data do not indicate an increased risk of SARS-CoV-2 infection or a deleterious course of COVID-19 among patients with IBD [6]. The effects of IBD treatment are controversial: high dose steroids appear to negatively influence the COVID-19 disease course, whereas most biologics and immunomodulators do not appear to have negative effects [7]. Moreover, immunosuppressive therapies can prevent a cytokine storm after an immunological reaction and are thus being investigated as therapeutic options for severe cases of COVID-19 [7,8].

As a response to COVID-19, governments worldwide have implemented hygiene practices, ranging from social restrictions to complete lockdowns [9]. Hospitals have postponed elective medical treatments to free up resources for the expected surge of severely ill patients with COVID-19 [10]. Likewise, appointments in the pediatric IBD outpatient department at our university were limited to acutely ill patients or those receiving infusion treatments only from the end of March through April.

The World Health Organization (WHO) has provided general recommendations for the COVID-19 pandemic [11]. However, IBD-patient-centered guidance has been scarce, thus leaving patients and their parents with high uncertainty about what actions they should take regarding COVID-19 and their disease, daily life, and IBD medication. The lives of patients with chronic diseases have been severely affected by the pandemic [12-14]. Except for findings from an Italian survey of an oncologic adolescent/young adult cohort from the pre-pandemic stage [15], little is known about the pediatric patient perspective in the COVID-19 pandemic.

To better understand the fears and behaviors of pediatric patients with IBD during the COVID-19 pandemic, we developed a survey for patients and their parents, on the basis of a survey previously published by our colleagues providing adult IBD services [13]. We assessed COVID-19 exposure, information sources, patient behavior, fears, and physician contact among pediatric patients with IBD and their parents/caregivers in May and June of 2020.

MATERIALS AND METHODS

Patient recruitment

Families of pediatric patients with IBD from the Pediatric Department of the Jena University Hospital, Germany, were asked to complete a paper-based survey. Each family received one patient survey and one parent survey to complete. The time of recruitment was between May 28 and July 1, 2020.

The survey from a previously published adult IBD cohort [13] was modified for pediatric patients and their parents. Data regarding demographics (age and sex), social situation (home schooling or home office), IBD diagnoses, comorbidities, and current IBD treatment

were assessed. Further questions focused on the main source of information regarding COVID-19, the type of physician contact, the use of personal protective equipment (PPE), and hand hygiene. Participants were asked to rate their responses to 13 COVID-19-related statements concerning personal fears, behavior, and need for information on a 5-point Likert scale (**Supplementary Material 1 and 2**). The pediatric surveys were validated for comprehensibility with three children and three adolescents, who were asked about terminology and were requested to actively reflect on the questions.

This study was conducted in accordance with the Declaration of Helsinki and was approved by the ethics committee of the Jena University Hospital (2020-1733_2-Reg). All participants, including both pediatric patients and their parents, provided written informed consent before inclusion in the study.

Statistical analysis

Statistical analysis was performed in IBM SPSS Statistics for Windows, Version 23.0 (IBM Co., Armonk, NY, USA), and figures were generated in Microsoft Excel 2013 (Microsoft, Redmond, WA, USA). To assess statistical differences in continuous data between dependent samples (pediatric IBD patients vs. parents), a non-parametric Wilcoxon signed-rank test was used. The McNemar test was applied for discrete data. All results with $p < 0.05$ in two-sided tests were considered statistically significant.

RESULTS

Patient recruitment and SARS-CoV-2 exposure

A total of 89 families were contacted, and 47 families responded (52.8% response rate). Among these families, 43 returned both parent and patient surveys, 3 returned only the patient survey, and 1 returned only the parent survey. Altogether, 90 surveys (46 pediatric patients with IBD and 44 parents/caregivers of pediatric patients with IBD) were analyzed. No participants reported testing positive for SARS-CoV-2, whereas one parent reported contact with a person who had tested positive (**Supplementary Table 1**).

Demographic data

We sent only one parent survey per family. The mean age of the parents ($n=44$) was 45 years, and most parent participants were female (89%). The mean family size was four members. At the time of the survey, 35% of parents were working from home (**Table 1**).

The mean age of the participating patients ($n=46$) was 15 years (ranging from 7 to 19 years), and slightly more boys (56.5%) than girls (43.5%) participated. Among the patient participants, 91% were home-schooled. Most of the cohort of pediatric patients with IBD (79%) had no comorbidities, and primary sclerosing cholangitis was the most common comorbidity (12.6%) (**Supplementary Table 2**). One-fifth (21.7%) of the patients stated that they smoke regularly. Less than one-third (29.8%) of the patients reported a current flu vaccination.

Disease characteristics and medication

Among the patients surveyed, 74.5% had Crohn's disease, 17% had ulcerative colitis, and 8.5% had unclassified IBD (**Table 1**). At the time of the survey, most patients (77.8%) reported that they were in clinical remission, whereas 15.6% reported mild activity. Only one patient had a flare-up.

Table 1. Demographics and characteristics of pediatric patients with IBD and their parents

Characteristic	Value
Parent age	45.00±5.33
Parent sex	
Not available	2 (4.5)
Female	39 (88.6)
Male	3 (6.8)
Parent occupation	
Home office	15 (34.9)
Working away from home	20 (46.5)
Not working	8 (18.6)
No information	1 (2.3)
Family members in the household	4.00±1.16
Patient with IBD characteristics	
Patient age	15.00±2.96
Patient sex	
Female	20 (43.5)
Male	26 (56.5)
Patient occupation	
School at home	42 (91.3)
Working away from home	4 (8.7)
Patient smoking status	10 (21.7)
Influenza vaccination	14 (29.8)
Number of comorbidities	
None	37 (78.7)
1	6 (12.8)
2	2 (4.3)
3	2 (4.3)
Type of IBD	
Crohn's disease	35 (74.5)
Ulcerative colitis	8 (17.0)
IBDU	4 (8.5)
Subjective IBD activity	
Quiescent	35 (77.8)
Mildly active	7 (15.6)
Chronically active	2 (4.4)
Flare-up	1 (2.2)
Current IBD medication	
Cortisol	3 (6.4)
Mesalazine	17 (36.2)
Anti-TNF	15 (31.9)
Vedolizumab	3 (6.4)
Ustekinumab	1 (2.1)
Azathioprine	22 (46.8)
Methotrexate	5 (10.6)
Modulen monotherapy	0 (0.0)
Modulen addition	7 (14.9)
Number of Immunosuppressants	
0	10 (21.3)
1	25 (53.2)
2	12 (25.5)

Values are presented as mean±standard deviation or number (%).

IBD: inflammatory bowel disease, IBDU: IBD unclassified, anti-TNF: anti-tumor necrosis factor alpha therapy.

Most of the pediatric patients with IBD participating in this study were receiving immunosuppressive therapy: only 21.3% of the patients had no therapy, 53.1% of the patients were taking immunosuppressive medication, and 25.1% were receiving two immunosuppressive agents. Overall, azathioprine (46.8%) was the most commonly used medication. Among patients receiving antibody treatment (40.4% of all patients), anti-tumor necrosis factor therapies were the most common (31.9% of all patients).

COVID-19 information sources and demand

In the patient group, the primary source of information on how to cope with COVID-19 was their parents (43%) (Fig. 1), and this was followed by television (41.3%). Social media platforms were also highly important, at 39.1%. The parents used internet news websites as their primary source of information (52.2%), and this was followed by television (39.1%) and the German public health institute (Robert Koch Institute) (32.6%). Unexpectedly, IBD-specific sources of information, such as IBD self-help groups and treating IBD physicians, ranked with very low importance in both groups. Significant differences between pediatric patients and their parents were observed in the use of social media (39.1% vs. 10.9%, $p=0.003$), newspapers (10.9% vs. 30.4%, $p=0.02$), and public health institutes (13% vs. 32.6%, $p=0.025$) (Fig. 1). Most patients and parents felt well informed about the coronavirus pandemic (Q1, Fig. 2). The parents also felt sufficiently informed about the influence of COVID-19 on IBD (Q2), and 54% agreed to the statement “I feel sufficiently informed about the consequences of coronavirus on my child with IBD.”

Fear of infection

The fear of being infected with COVID-19 (Q3) was significantly higher in the patient group than in the parent group, with a median response of ‘neutral’ vs. ‘disagree,’ respectively. However, the parents had high fear (62% agreed and 19% disagreed with Q3, median ‘agree’) of their children being infected. This fear was significantly higher than the fear for oneself among both children and parents (Fig. 3). Parents reported the highest fear toward the school environment as a source of infection (median ‘agree’), at a significantly higher level ($p=0.016$) than the pediatric IBD patients (median ‘neutral’). In general, the fear of being infected at health care facilities (hospital [Q5] and private practice [Q6]) and at public places such as supermarkets (Q7) was low in both groups, with a median ‘disagree’ (Fig. 3). A wide range of opinions was observed regarding the negative effects of IBD medication on SARS-CoV-2 infection (Q4), with an overall median ‘neutral’ for both groups (Fig. 3).

Health care availability

In both pediatric patients and their parents, there was no substantial fear of a lack of access to health care services during the COVID-19 pandemic (Q12, Fig. 3). None of the participants

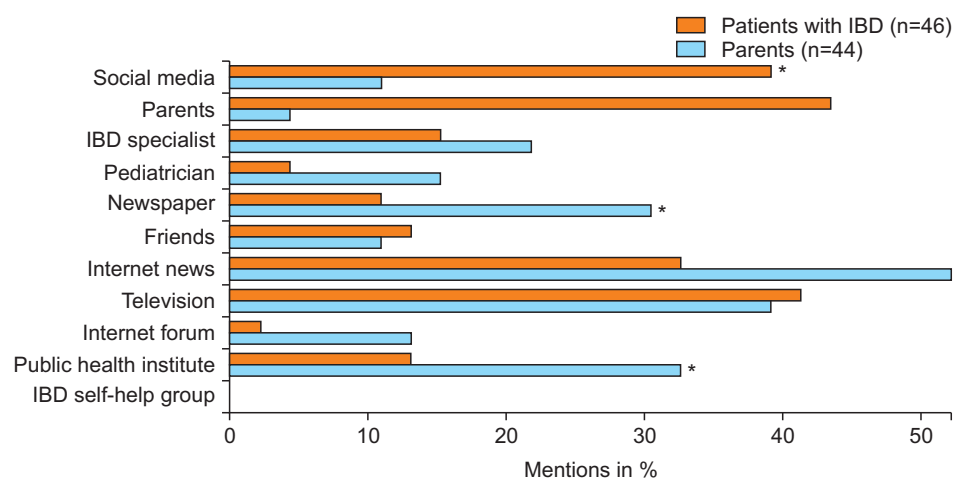


Fig. 1. Source of information for behavioral guidance during the COVID-19 pandemic. IBD self-help group, public health institute=Robert Koch Institute (McNemar test, * $p<0.05$). COVID-19: coronavirus disease 2019, IBD: inflammatory bowel disease.

How COVID-19 Influences the Lives of Pediatric Patients with IBD and Their Parents

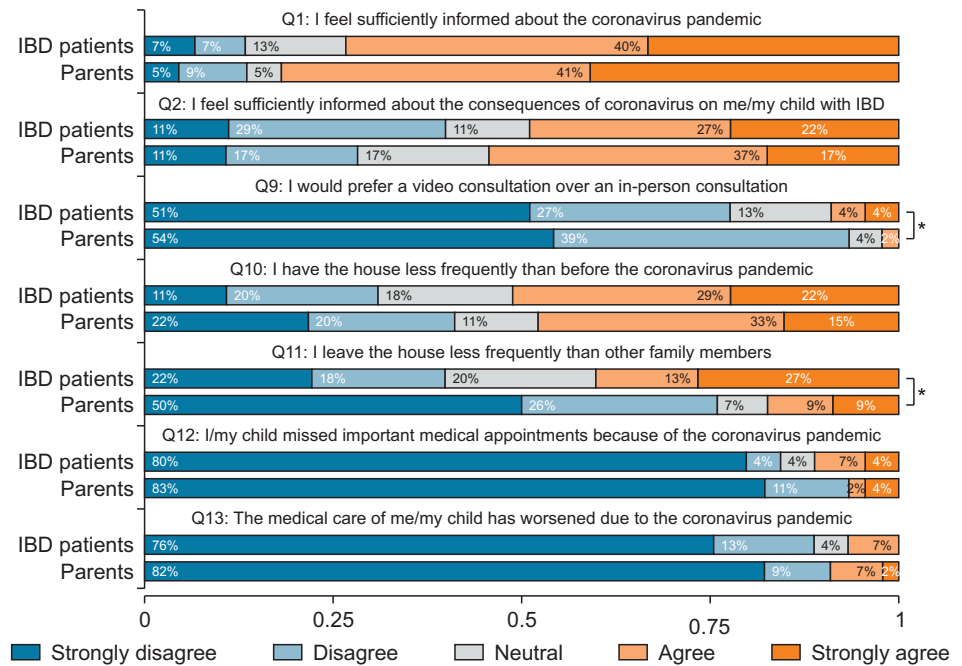


Fig. 2. Results of Likert-scale question responses concerning information needs/behavior during the coronavirus pandemic. Results are illustrated in 100% bars. Each fraction of each bar corresponds to the percentage of mentions for one Likert-scale option in the respective group (Wilcoxon signed-rank test, * $p < 0.05$). IBD: inflammatory bowel disease.

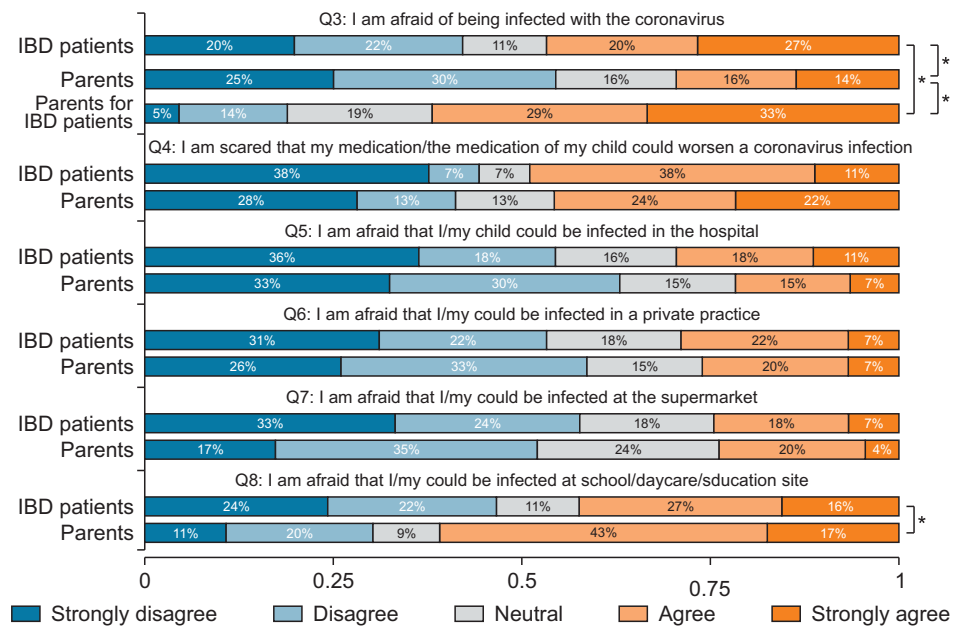


Fig. 3. Results of Likert-scale question responses concerning fears during the coronavirus pandemic. Results are illustrated in 100% bars. Each fraction of each bar corresponds to the percentage of mentions for one Likert-scale option in the respective group (Wilcoxon signed-rank test, * $p < 0.05$). IBD: inflammatory bowel disease.

felt that they had missed any important medical appointments (Q13) (Q12 and Q13, all median ‘highly disagree’) (Fig. 2). Among the 47 families surveyed, 14 (31.8%) contacted a physician to speak about COVID-19. The primarily consulted physician was the IBD specialist (64%).

Pediatric IBD patient behavior during the COVID-19 pandemic

None of our surveyed pediatric patients reported stopping any IBD medication on their own account. A total of 28.9% of the children and 25.6% of the parents reported wearing PPE, such as surgical face masks, in places that did not mandate such equipment (**Supplementary Table 1**). Personal hand hygiene was enhanced in both groups (84% of patients and 95.3% of parents). Patients with IBD reported leaving the house less frequently than they did before the COVID-19 pandemic (Q10, median 'agree'), and 40% of pediatric patients with IBD reported leaving the house less frequently than other household members (Q11), as opposed to only 18% of surveyed parents (median 'neutral' vs. 'disagree,' $p=0.001$). Neither parents nor patients with IBD preferred medical video consultations to in-person consultations (Q9, both medians 'strongly disagree').

DISCUSSION

COVID-19 can occur in people of all age groups. However, children and adolescents often show a more benign evolution, with cold-like symptoms and faster recovery [16,17]. Nonetheless, our assessment of the perspectives of almost 50 pediatric patients with IBD and their parents/caregivers regarding COVID-19 showed that parents had high fear of their children being infected with SARS-CoV-2, which exceeded the pediatric patients' own fear. Nonetheless, half of the pediatric patients with IBD reported a fear of being infected. Their level of fear was comparable to that of young-adult IBD patients earlier in the pandemic (April 2020), as extracted from a previous IBD study (data not shown) [13]. Children and adolescents have been shown to be physically and emotionally more dependent on their parents after diagnosis with IBD [18-20]. Thus, the overprotective fear of the parents during the COVID-19 pandemic will probably lead to more cautious patient behavior. For example, more than 80% of pediatric patients with IBD and their parents followed WHO recommendations and increased their hand hygiene. Most patients also reported leaving the house less frequently than they did before. When leaving the house, almost one-third of pediatric patients with IBD reported going beyond local regulations by wearing PPE, even in places where such use is not mandatory.

Although most physicians expect patients to have a high demand for information, the surveyed patients stated that they were sufficiently informed about COVID-19 and its influence on IBD. However, examination of the preferred source of information indicated that pediatric patients with IBD primarily sought guidance from their parents, followed by television and social media outlets. The parents of pediatric patients with IBD—the children's primary guides—mainly consulted television and internet news sites for information. IBD-centered sources of information, such as pediatric gastroenterologists or IBD self-help groups, were reported to be of low importance. Similar behavior has also been observed in adult patients with IBD during the COVID-19 pandemic [13,14]. This finding should encourage physicians to actively approach pediatric patients with IBD and their parents to convey IBD-centered COVID-19 information. Fortunately, all patients continued their therapy regimens. This finding is consistent with the high compliance rate observed in the adult IBD population [13,14] and is in accordance with the current recommendations of the European Crohn's and Colitis Organization (ECCO). Further valuable evidence for this recommendation comes from the international Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE-IBD) registry, which has collected the outcomes of >2,700 cases of COVID-19 with IBD (as of November 2020) [21].

A major concern for societies after a lockdown is a new wave of infections caused by children returning to school. Our study demonstrated that the fear of being infected in school was a major concern for parents. In contrast, the pediatric patients with IBD feared the school environment far less. This result may have arisen because all participating children were home-schooled at the time of the survey. School is the main source of children's social life beyond their families, and companionship is vital for psychological well-being and development [22]. Increasing evidence indicates the substantial psychosocial burden caused by social isolation due to the COVID-19 pandemic [23]. The fear of going to public places or medical facilities was lower than expected or previously observed [13], possibly because of newly implemented safety measures for medical facilities (such as PPE, symptom checklists, and temperature measurements). These findings and the overall satisfaction with health care availability during COVID-19 reported in this survey may account for the low acceptance of video consultation options in patients and parents.

As with any other research, this study has several limitations that warrant discussion. This was a single-center study. Differences in sociocultural background, national health services, and pandemic severity in other countries must be considered in interpreting and generalizing these results. The decreasing infection rates and slow relaxation of governmental restrictions at the time of the survey may lead to less cautious behaviors and sentiment. Reading age was not assessed among pediatric patients, and caregivers might have assisted younger children with survey completion, thus possibly influencing the responses.

The strengths of this study include the good response rate and the collection of views from two sides, i.e., parents and patients. To our knowledge, this is the first study reporting the perceptions, attitudes, and behaviors of pediatric patients with IBD and their parents in the COVID-19 pandemic.

In conclusion, parents of children with IBD have high fear of their children being infected with SARS-CoV-2, and school is perceived as the most hazardous environment. Although access to medical care has been hindered by the pandemic, patients are content with their care and feel sufficiently informed about COVID-19; however, they primarily consult non-IBD-centered information sources. Resilience among patients, as evidenced by enhancing hand hygiene, staying at home, and adhering to IBD medication regimens, was observed in this cohort. Thus, our patients and their parents are coping well with the unprecedented challenge of COVID-19.

ACKNOWLEDGEMENTS

We thank Gabriele Steidl for support in distributing the survey.

SUPPLEMENTARY MATERIALS

Supplementary Material 1

English translation of the patient survey

[Click here to view](#)

Supplementary Material 2

English translation of the parent survey

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Supplementary Table 1

Results of closed-ended questions and statements concerning coronavirus exposure and behavior/coping strategy (McNemar test, in bold $p < 0.05$)

[Click here to view](#)

Supplementary Table 2

Pediatric patients with IBD comorbidities

[Click here to view](#)

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