Original Research Article

Burden andHealthcareNeeds of Caregivers of Children with Inflammatory Bowel Disease after the End of China's Dynamic Zero-COVID-19 Policy: A singlecenterstudy

Abstract

Background

Following China's decision to end its dynamic Zero-COVID-19 Policy in December 2022, COVID-19 infections surged in the subsequent month. Presently, there exists a scarcity of epidemiological data regarding COVID-19 in Chinese children with inflammatory bowel disease (IBD). Additionally, there is a lack of information regarding the burden of caregivers of these children and the specific healthcare requirements for home care.

Methods

From January 18 to February 1, 2023, an anonymous online survey was conducted to gather data on the demographics of participants, their experiences with COVID-19 infection, caregiver burden, and the healthcare needs of children with IBD.

Results

The study obtained a response rate of 73.06% from participants, consisting of 98 (54.75%) males and 81 (45.25%) females. The average age (SD) of the respondents was 11.44 (4.29) years old. Among the 179 children with IBD, 116 (64.80%) experienced COVID-19 infection.

Caregivers reported facing various burdens, with financial burdens being the most significant, followed by psychological, physical, and time burdens. Overall, caregivers of COVID-19-uninfected children experienced a heavier burden compared to those with COVID-19-infected children. Significant differences were observed in terms of physical burden (P=0.01) and time burden (P=0.03) between caregivers of COVID-19-infected and uninfected children.

The most needed health service for caregivers was found to be telemedicine service (Mean=3.66), followed by knowledge concerning COVID-19 in children with IBD (Mean=3.55), vaccination recommendations (Mean=3.40), diet and nutrition care (Mean=3.37), psychological counseling and care (Mean=2.51), care for perianal lesions (Mean=2.09), and care for wounds or stomas (Mean=1.84). However, there were no significant differences in healthcare needs between caregivers of COVID-19-infected and uninfected children.

Conclusions

In this study, despite more than half of the children being infected with COVID-19, the symptoms were mostly moderate, with no severe cases observed. Caregivers identified financial burden as the primary challenge, with caregivers of non-infected children experiencing a greater burden than those of infected children. There was a significant demand for telehealth services, highlighting the need for further development in China to meet the increasing medical care requirements during the pandemic.

Keywords: COVID-19, economic challenges, quarantine, potential human rights

Background

The global outbreak of COVID-19, caused by the SARS-CoV-2 virus in 2019, has resulted in over 99 million confirmed cases and more than 120 thousand deaths worldwide. (1). This pandemic has posed significant social and economic challenges over the past three years.China's zero-COVID policy, implemented until December 2022, aimed to completely eliminate COVID-19 transmission within the country. This strategy involved the implementation of multilayer nonpharmaceutical intervention protocols(2), including: a.Stringent domestic travel restrictions and border control measures to interrupt the chain of transmission and prevent imported cases; b. UtilizationofHealth QR code forcontact tracing based on GPS positioning technology to swiftly identify potential infection cases; c. Implementation of strict quarantine and health monitoring programs, requiring close contacts of infected individuals to undergo COVID-19 testing and isolate until deemed safe to reintegrate into society.The majority of interventions are mandatory, with law enforcement holding individuals accountable for violating established protocols. Although these measures have faced criticism for their strictness and potential human rights implications, they have proven effective in reducing virus transmission and fatalities, resulting in a low infection rate among the general population until December 2022 (3, 4). Additionally, the Chinese government initiated a free COVID-19 vaccination program, with the first round of vaccinations administered in January 2021 (5).In February 2022, China introduced its first booster immunization, and in November of the same year, a second booster shot was recommended, particularly for individuals aged 60 and above with underlying health conditions and compromised immunity.

Countries worldwide, including France, Spain, the United States, Italy, Denmark, Iran, and Brazil, have reported the prevalence of COVID-19 infection in individuals with IBD (6). Moreover, there exists a collaborative global effort to share IBD data through the SECURE-IBD database (7). However, it is noteworthy that 84.2% of the available data originates from Caucasian individuals (8),indicating a lack of diversity in the existing dataset. Furthermore, there is a scarcity of data regarding the impact of COVID-19 on Chinese children with IBD, and the extent of harm caused by the virus within this specific population remains insufficiently understood and reported.

The impact of COVID-19 on children with IBD has yielded conflicting data. Certain studies have indicated that individuals with IBD, particularly those receiving immunosuppressive treatment, may be at a higher risk of experiencing severe infections, including COVID-19. (9-10)However, an additional study reported contrasting findings, suggesting that individuals with IBD did not exhibit an elevated occurrence of COVID-19 or an increased risk of severe COVID-19 cases. (11)Nevertheless, one undeniable aspect is the significant impact on the social and psychological well-being of children and families. Research has demonstrated that the COVID-19 pandemic has intensified stress levels within these families, leading to fear and excessive protective behaviors.(12-14)Furthermore, parents who have children with inflammatory bowel disease (IBD) play a crucial role in ensuring their children's adherence to medication, scheduling appointments, and fostering connections with medical experts. Consequently, these parents may have to make personal sacrifices and allocate their own time to fulfill their children's requirements. (15) According to a survey conducted by Flexjobs, approximately 15% of employed parents

decided to resign from their jobs during the pandemic. (16) Our study aims to report the burden and healthcare needs ofcaregiversofchildrenwith IBDat the peak ofthepandemic after the abandonment of the dynamic Zero-COVID-19 Policyin China.

Materials and Methods

Study design

The cross-sectional descriptive study was conducted over a period spanning from January 18, 2023, to February 1, 2023.

Participants, inclusion, and exclusion criteria

Inclusion criteria for the study consisted of: 1) being the primary caregiver of a child diagnosed with IBD, and 2) expressing a willingness to take part in the study. Caregivers were excluded if they met any of the following criteria: 1) experiencing difficulties in reading, or 2) having a history of mental illness.

Data collectionandprocedure

The survey items were developed by the researchers after conducting an extensive review of the existing literature and consulting subject-matter experts for their recommendations. Data for the study were collected through a structured questionnaire, which encompassed the following sections: a) general demographic information of children diagnosed with IBD, b) characteristics of IBD, c) information on COVID-19 infections, d) assessment of caregiver burden, and e) evaluation of caregivers' healthcare needs subsequent to the discontinuation of the dynamic Zero-COVID policy.

The caregiver burden was measured using a Likert scale ranging from 1 to 5, with the following scale points: None=1, A little=2, Somewhat=3, A lot=4, Enormously=5. Similarly, the healthcare services required by caregivers were assessed using a Likert scale ranging from 1 to 5, with the scale points representing Never=1, Rarely=2, Sometimes=3, Often=4, Always=5. Additionally, participants who rated their burden as 3 points or higher were requested to provide further details regarding the extent and specific aspects in which they perceived an increase in their burden. The questionnaires were administered to the primary caregivers of the children. To ensure the usability and response time of the surveys, a pilot evaluation was conducted by five caregivers.

The survey was conducted online using an anonymous questionnaire, which was distributed through the "Survey Star" online platform developed by Changsha Ran Xing Science and Technology in Shanghai, China. The questionnaire was sent to a total of 245 caregivers via the WeChat IBD interactive group, which was established by the National Children's Gastroenterology Department of Children's National Medical Center. This interactive group included IBD clinic specialists, IBD specialist nurses, children with IBD, and their caregivers.Prior to receiving the questionnaire, participants were provided with a letter of invitation that emphasized the voluntary nature of their participation. The letter assured them of the confidentiality of their responses and the freedom to withdraw from the study at any time. Ethical approval for this study was obtained from the Research Ethics Board at the Children's Hospital of Fudan University.

Statistical Analysis

The data analysis was performed using the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) for Windows, version 26.0. Continuous variables were summarized as median (interquartile range) and mean ± standard deviation (SD). Categorical variables were reported as counts and percentages. Pairwise comparisons were conducted using the Mann-Whitney test. Statistical significance was determined as $P \leq 0.05$.

Results

Demographic characteristics

Demographicscharacteristics of children listed in Table 1. A total of 245 questionnaires were distributed to caregivers of children, and 179 (73.06%) participants returned their completed questionnaires for analysis. The demographic data reported by the primary caregivers included 98 (54.75%) boys and 81 (45.25%) girls. The mean age at baseline was 11.44 (SD=4.29). In terms of the types of inflammatory bowel disease (IBD), the study included children with Crohn's disease (CD) accounting for 70.39%, ulcerative colitis (UC) accounting for 20.11%, and undetermined IBD (U-IBD) accounting for 9.5%.

Table 1Demographics and characteristics of caregiverandchildren with IBD

Characteristic	n/median	Percentage(%)/IQR
Sex		
Male	98	54.75
Female	81	45.25
Age,y	12	8, 15
Diagnosis		
CD	126	70.39
UC	36	20.11
IBDU	17	9.50
Education		
Preschool	20	11.17
Primary school	51	28.49
Secondary school	53	29.61
High school	32	17.88
Drop out	23	12.85
Ethnicity		
Han	174	97.21
Hui	2	1.12
Zhuang	2	1.12
Miao	1	0.56
Region*		
Eastern district	116	64.80
South district	3	1.68
Central district	27	15.08
North district	20	11.17
Northwest district	1	0.56
Southwest district	4	2.23
Northeast district	8	4.47

*Eastern district: Shanghai(n=38), Anhui province(n=24), Jiangsu province (n=28), Zhejiang province (n=15), Fujian province(n=7), Jiangxi province (n=2), Shangdong province (n=2);South district: Guangdong province (n=2), Guangxi province (n=1); Central district: Heinan province(n=20), Hubei province (n=4), Hunan province(n=3); North district: Heibei province

(n=10),Shanxi province (n=6) ,Tianjin province(n=4);Northwest district: Gansu province (n=1); Southwest district:Sichuan province (n=2), Yunnan province (n=2); Northeast district:Jilin province (n=4) , Liaoning province (n=2), Heilongjiang province (n=2)

The average age of diagnosis was found to be 8.14 (SD=4.79). Regarding medication usage, 84.92% of children are treated with oral medications for inflammatory bowel disease (IBD), 58.10% of children are treated with biologics, and 54.74% of children are treated with a combination of oral medications and biologics.The comorbidities observed among the children included chronic liver disease, diabetes mellitus, pancreatitis, congenital heart disease, juvenile idiopathic arthritis, ankylosing spondylitis, asthma, Hirschsprung's disease, renal dysfunction, and Bruton syndrome. For more detailed information, please refer to Table 2.

Table 2IBDcharacteristics

Variables	N/Mean	Percentage(%)/SD
Age of diagnosiswith IBD(n=179)	8.14	4.79
Take medicine for IBD(n=179)		
yes	152	84.92
no	27	15.08
Oralmedicaltreatmentfor IBD(n=152)		
5-aminosalicylic acid	120	67.04
azathioprine	46	25.70
steroid	42	23.46
probiotics	37	20.67
thalidomide	27	15.08
methotrexate	14	7.82
ciclosporin	6	3.35
omeprazole	10	5.59
tofacitinib	5	2.79
Mercaptopurine	1	0.56
Biological(n=104)		
infliximab	80	76.92
adalimumab	11	10.58
ustekinumab	10	9.62
vedolizumab	3	2.88
Comorbidity(n=179)		
chronicliverdisease	3	1.68
diabetes mellitus	2	1.12
pancreatitis	2	1.12
congenital heart disease	1	0.56
juvenile idiopathic arthritis	1	0.56
ankylosing spondylitis	1	0.56
asthma	1	0.56
Hirschsprung's disease	1	0.56
renal dysfunction	1	0.56
Bruton syndrome	1	0.56

Table 3 presents the relevant information regarding COVID-19 infections.Out of the children with IBD, 116 (64.80%) were reported to have been infected by COVID-19 during the pandemic. Among those infected, only 1 (0.87%) experienced a second infection. In terms of seeking medical care, the majority of children (83.62%) opted for self-quarantine at home with home-

based health care, and no children with IBD required admission to the intensive care unit (ICU) due to COVID-19 infection.

Symptoms that emerged during COVID-19 infection comprised fever, cough, weakness or inertia, sore throat, muscular soreness, hypogeusia or ageusia, vomit, nausea, hyposmia or anosmia, hematochezia, polypnea, perianal lesion andarthralgia. Only 7 (6.03%) out of the 116 caregivers reported a perceived aggravation of their children's IBD-related symptoms, specifically diarrhea, blood in the stool, weight loss, and perianal lesions. Among the 116 children with IBD, 10 underwent gastrointestinal endoscopy either during or after their COVID-19 infection.Regarding medication usage, 24 (20.69%) children suspended their IBD treatment due to COVID-19 infection. Additionally, 42 (24.02%) children experienced a suspension of their follow-up appointments.

Table 3 COVID-19 infection-related data

Variables	N	Percentage(%)
Infected with COVID-19 (n=179)		
Yes	116	64.80
No	63	35.20
Thenumber of times of COVID-19infection(n=179)		
1	115	99.13
2	1	0.87
COVID-19 Vaccination (n=179)		
Yes	72	40.22
No	102	59.78
Visit doctor due to COVID-19 infection (n=116)		
Yes	19	16.38
No	97	83.62
Hospital service (n=116)		
Out-patient department	9	7.76%
In-patient department	6	5.17%
Emergency	4	3.45%
Admitted into ICU (n=116)		
Yes	0	0.00
No	116	100.00
New onset symptoms during COVID-19 infection(n=116)		
fever	104	89.66
cough	63	54.31
weakness or fatigue	51	34.48
sore throat	26	22.41
muscular soreness	13	11.21
hypogeusia or ageusia	12	10.34
vomit	9	7.76
nausea	7	6.03
hyposmia or anosmia	3	2.59
hematochezia	3	2.59
polypnea	2	1.72
perianal lesions	1	0.86
arthralgia	1	0.86
Perceive aflare-up of children's IBD symptoms during COVID-19 infection (n=116)		
Yes	7	6.03
No	109	93.97
Symptoms aggravated after COVID-19 infection(n=116)		
Diarrhea	6	5.17

Hematochezia	5	4.31
Weight loss	1	0.86
Perianal lesions	1	0.86
Gastrointestinal endoscope during or after COVID-19 infection(n=116)		
Yes	10	8.62
No	106	91.38
Result of gastrointestinal endoscope (n=116)		
Gastritis	6	5.17
Colitis	6	5.17
Ileitis	5	4.31
No abnormalities	3	2.58
Suspend the IBD medication use(n=116)		
Yes	24	20.69
No	92	79.31
Suspend the IBD follow-up visits(n=116)		
Yes	42	24.02
No	109	60.89
Don need follow-up	28	15.64
The reason for suspending the IBD follow-up(n=42)		
lack of access to medical care service	12	28.57
Child was infected by COVID-19	4	9.52
Caregiver was infected with COVID-19	3	7.14
Difficulty in making an appointment	2	4.76
Inpatient bed shortage	3	7.14

The COVID-19 pandemic's caregiver burden was shown in Table 4 for reference.

Table 4 Family care burdenafter the end of China's Dynamic Zero-COVID-19 Policy（n=179）

	1-None N(%)	2-A little N(%)	3-Somewhat N(%)	4-A lot N%	5-Enormously N(%)	Mean
I feel that the physical burden of caring for children at home increased (N=179)	21(11.73)	69(38.55)	52(29.05)	25(13.97)	12(6.70)	2.65
To what extent does the physical burden increase (N=89)	I feel tired of taking care of my child	More family members need to be involved in care	More people from outside the family (e.g. relatives, friends) is required	Need to hire someone to take care of your child	Fail to care for children home	--
	40(44.94)	38(42.70)	5(5.62)	4(4.49)	2(2.24)	--
I feel that the time burden of caring for children at home increased(N=1	21(11.73)	72(40.22)	49(27.37)	29(16.20)	8(4.47)	2.61

79)						
To what extent does the time burden increase (N=86)	Need to spend more time caring for my child than ever before	Need to spend most of the day caring for my child	Find it difficult to continue my work	need to stop working to care for my child	Don't have any time except to care for my child	--
	46(54.48)	14(16.27)	10(11.63)	10(11.63)	6(6.98)	--
I feel that the psychological burden of caring for children at home increased （N=179）	16(8.94)	57（31.84）	67 (37.43)	32（17.88）	7（3.91）	2.76
In what aspect does the psychological burden increase (N=106)	Worry about child getting infection or reinfection of COVID-19	Worry about the gastrointestinal symptoms aggressive	Worried about the children can't reach the medical resource	Worried about child is negatively affected psychologically	Worried about the delay of school and other outdoor activities	--
	94(88.67)	82(77.36)	67（63.21）	33（31.13）	53（50.00）	--
I feel the financial burden of taking care of my children at home increased (N=179)	13(7.3)	70（39.1）	45（25.1）	38（21.2）	13（7.3）	2.82
In what aspect does the financial burden increase(N=96)	Cost in medical treatment	Cost in personal protective equipment	Cost in transportation	Cost in accommodation	Cost in diet	--
	73(76.04)	45（46.88）	45（46.88%）	38（39.58）	5（5.21）	--

Comparing the burden of COVID-19-infected and uninfected children's caregivers was shown in Table 5.

Table 5. Comparison of the physical, time, psychological and financial burden in children with IBD infected and uninfected with COVID-19

	Infected with COVID-19, Mean	Not infected with COVID-19, Mean(SD)	P-value
Physical burden	2.49	2.96	0.01

Time burden	2.49	2.84	0.03
Psychological burden	2.66	2.94	0.07
Financial burden	2.72	3.02	0.09

Table 6 presents the medical services needed for in-home care.

Table 6 Medical care services caregivers needin-homecare after the end of China's Dynamic Zero-COVID-19 Policy（n=179）

	1-Never N(%)	2-Rarely N(%)	3-Sometimes N(%)	4-Often N%	5-Always N(%)	Mean
1. Prevention techniques for COVID-19, post-infection treatment, and recovery promotion techniques, etc.	19(10.61)	23(12.85)	28(15.64)	58(32.40)	51(28.49)	3.55
2. Care of perianal lesions (suchas perianal abscess, anal fistula and skin tags, etc.)	96(53.63)	32(17.88)	11(6.15)	19(10.61)	21(11.73)	2.09
3. Wound/stoma care (suchas IBD-related wounds, peristomal dermatitis, gastrostomy and enterostomy, etc.)	111(62.01)	30(16.76)	7(3.91)	18(10.06)	13(7.26)	1.84
4. Psychological counseling and care (including psychological assessment, counseling, medication management, etc.)	62(34.64)	35(19.55)	32(17.88)	28(15.64)	22(12.29)	2.51
5. Diet and nutrition care (includes assessing children's nutritional issues, giving dietary recommendations, and, if needed, referring them to specialized support services, etc.)	35(19.55)	18(10.06)	24(13.41)	49(27.37)	53(29.60)	3.37
6. Vaccination recommendations for IBD children who get COVID-19 infection	35(19.55)	17(9.50)	16(8.94)	63(35.20)	48(26.82)	3.40
7. Telemedicine(including online prescription management, labandimaginginterpretingand nursing direction, etc.)	20(11.17)	14(7.82)	27(15.08)	64(35.75)	54(30.16)	3.66

Table 7 compares the needs for medical services in IBD children infected and uninfected with COVID-19.

Table 7 Comparison of the needs formedical services in IBD children infected and uninfected with COVID-19

	Infected with COVID-19，Mean(SD)	Not infected with COVID-19，Mean	P-value
Knowledge concerning COVID-19 in children with IBD (including emphasizing precautions, post-infection treatment, and recovery promotion strategies)	3.55	3.59	0.84
Care of perianal lesions (including perianal abscess, anal fistula and skin tags, etc.)	2.09	2.14	0.53
Wound/stoma care (including IBD-related wounds/ gastrostomy/enterostomy)	1.84	1.90	0.63
Psychological counseling and care (including assessment of anxiety, depression, etc., and referral to specialist support services if necessary)	2.51	2.62	0.52
Diet and nutrition care (including assess children's nutritional problems, provide dietary advice, and refer them to specialist support services when necessary)	3.37	3.17	0.21
Vaccination recommendations for IBD children who get COVID-19 infection	3.40	3.37	0.92
Online healthcare (remote provision of medicationdosingadjustment, nursing direction through internet)	3.66	3.57	0.70

Discussion

In early December 2022, China made the decision to abandon its dynamic zero-COVID policy, gradually opening its borders and transitioning to coexist with SARS-CoV-2. Consequently, the number of COVID-19 infections in China quickly escalated. This study sheds light on the impact of the pandemic on children with IBD, revealing that a significant proportion of 64.80% experienced COVID-19 infections. This figure surpasses the reported rates in many other countries worldwide, highlighting the substantial impact of the pandemic on this particular population (17). Themorerigoroustestingprotocolin Chinaand relatively low vaccination rate (40.22%) among IBD children compared to the total vaccination rate in China (＞85%) maybe the reasons for the higher infection rate (18).

Vaccination wasconsidered a pivotal strategy to prevent the spread of COVID-19 and ultimately end the pandemic(19-20). The Chinese government provides its citizens with three types of free vaccines: the single-dose adenovirus vector vaccine (Convidecia), the two-dose inactivated vaccines (CoronaVac, BBIBP-CorV, and COVILO), and the three-dose recombinant subunit vaccine (Zifivax). (1-2) A large-scale randomized controlled study demonstrated that two inactivated SARS-CoV-2 vaccines developed in China had efficacy rates of 72.8% and 78.1%, respectively, in preventing symptomatic cases of COVID-19. (3) Furthermore, another study revealed that the CoronaVac vaccine has an efficacy rate of 65.7%, which is lower than the efficacy rates of the Pfizer-BioNTech vaccine (98.1%) and the Moderna vaccine (98.1%).(4)

The acceptance of COVID-19 vaccination varies significantly among different nations. Some European countries have witnessed the presence of anti-vaccine movements, while China has not experienced a similar movement. However, the ongoing debate about vaccines continues in China. Research conducted in China indicates that the overall prevalence of COVID-19 vaccine hesitancy among individuals ranges from 8.40% to 35.5%. Surprisingly, over half of patients with IBD express indecisiveness regarding vaccination, as reported in studies (23-25). The concerns of patients regarding COVID-19 vaccines primarily revolve around safety, adverse reactions, personal hypoimmunity, and the efficacy and validity of the vaccines (25).Patients with IBD are believed to have lower rates of seroconversion due to both the use of immunosuppressants and the activity of the disease itself (26). However, a recent study has demonstrated that the efficacy of COVID-19 vaccination in patients with IBD is comparable to that in individuals without IBD and is not affected by the use of TNF inhibitors or corticosteroid therapy (27).Regarding the safety of COVID-19 vaccines, current research indicates that neither messenger RNA nor DNA vaccines are associated with IBD flare-ups, regardless of whether prior COVID-19 infection was present or not (28-30). This suggests that vaccination against COVID-19 does not pose an increased risk of exacerbating IBD symptoms.

Despite the high infection rate among pediatric children with IBD, the majority of cases exhibited mild symptoms such as fever, cough, weakness orfatigue, and sore throat. Encouragingly, no ICU admissions were reported in this study, suggesting that severe illness and complications were relatively uncommon among this population. The hospitalization rate among children with IBD was found to be low, at 5.17%. Interestingly, most families preferred to care for their children at home instead of seeking hospitalization. This could be attributed to the manageable nature of symptoms at home and the caregivers' fear about visiting medical facilities (31-33).However, it is important to note that a small percentage of caregivers (6.03%) reported a deterioration in intestinal symptoms, including diarrhea, hematochezia, and increased perianal lesions. A study conducted in Wuhan, China, indicated that 48% of COVID-19 patients experienced digestive symptoms, suggesting that the virus could invade the gastrointestinal tract and cause damage (34). This is further supported by research demonstrating the presence of viral RNA in stool samples even after respiratory samples tested negative (35,36).

IBD patients are considered to be more susceptible to infections, especially if they have active disease and are receiving immunosuppressive therapy (37). Furthermore, advancing age, the presence of comorbidities, systematic corticosteroids, and the use of sulfasalazine or 5-

aminosalicylates have been associated with severe outcomes of COVID-19 infection (38-40).A study conducted in New York City revealed a statistically significant increase in the prevalence of Crohn's disease approximately six months after the initial COVID-19 wave in 2020 (41). This finding highlights the need for further investigation in light of the Omicron wave, as it suggests a potential association between SARS-CoV-2 infection rates and future pediatric IBD cases. However, some studies have reported contrasting results, indicating that individuals with IBD do not have an increased risk of contracting COVID-19 compared to the general population and may even have a lower risk (42-43).Another cohort study has provided evidence that the different medications used for IBD do not have a detrimental effect on the risk of COVID-19 or severe COVID-19 outcomes (44).

It is worth noting that some individuals continue to experience health issues even years after recovering from COVID-19. Long-term follow-up studies have shown that at 3 and 6 months after infection, there is a significantly higher incidence of newly diagnosed post-infectious functional gastrointestinal disorders and disorders of gut-brain interaction in individuals who had COVID-19 compared to healthy controls (45). The relationship between IBD and COVID-19 is complex and still inconclusive. Further research is needed to investigate the influencing factors, and developing a prediction model may be necessary to address this issue effectively.

According to our research, caregivers typically endure more significant financial and psychological stress than time- and physical-related stress. This may be connected to COVID-19-related medications, personal protective gear, commuting, and accommodation costs.“Medicine hoarding frenzy” lastedforalongtimein Chinaduringthe pandemic, people tended to stockpilemuch medication on handto relieve their anxiety and fear. In addition, previous studies have shown that families frequently remove kids from the throng (31, 46), which mayreduce the use of public transportation and increases the use of private vehicles, raising transportation expenses.According to the data from the US, mental health symptoms also were increasing during the COVID-19 pandemic (47). This change was more intense for parents than for their non-parent counterparts (48).Mostcaregivers expressed concern that their child would be infected with COVID-19and that the disease would worsen intestine-related symptoms.

Contrary to our initial assumption, our findings reveal that caregivers of COVID-19-uninfected children experience greater physical, time, financial, and psychological burdens compared to caregivers of COVID-19-infected children. This unexpected result may be attributed to the inherent fear of the unknown and uncertainty that naturally arises in such situations. The constant threat of contracting the virus and the potential severe consequences weigh heavily on the minds of caregivers, resembling a "sword of Damocles" hanging over their heads. Consequently, they invest more time and effort in caring for their children and taking preventive measures against COVID-19, which ultimately leads to a higher burden on their shoulders.

Telemedicine services ranked as the highest priority among the medical care needs, consistent with previous studies (49-50). The outbreak of COVID-19 has led to the implementation of traffic regulations, with infected individuals being advised to stay at home or have their movements tracked,which has made accessing medical care more challenging.

Telemedicine interventions have played a crucial role in managing IBD during the pandemic and have demonstrated superior outcomes compared to standard care (51-52). China has placed a strong emphasis on expanding online healthcare services following the transition away from the zero-COVID policy, aiming to provide patients with the convenience of receiving medical consultations from their homes. Despite the establishment of more than 1,600 online hospitals on the Chinese mainland as of June 2021, serving over 239 million users, there is still an unmet demand among the country's population of 1.4 billion (53).As of this writing, many countries have already experienced the peak of new COVID-19 cases and fatalities and have started to resume their outpatient services. In contrast, Chinese people encountered difficulties in accessing appropriate medical care after a sudden and strict lockdown was implemented (54-55). With the world's largest population and a vast territory, China faces challenges in ensuring equitable distribution of medical resources due to income inequality, resulting in regional disparities. Telemedicine has emerged as a valuable solution, providing patients in remote areas with convenient and cost-effective access to advanced medical resources. It also simplifies the process for family members or friends to participate in medical appointments (56).

Conclusion

The study highlights the pressing necessity for tailored interventions to alleviate the financial burden and address the healthcare needs of caregivers of children with IBD in China, particularly during the ongoing COVID-19 pandemic. Policymakers and healthcare providers should consider implementing policies to reduce out-of-pocket expenses associated with IBD care and enhance the availability and accessibility of IBD specialists. These measures can significantly improve healthcare access and affordability for affected families. Furthermore, the adoption of telehealth services can help overcome barriers to healthcare access, such as geographic distance and limited availability of healthcare providers, especially in countries characterized by large territories and substantial urban-rural disparities. By embracing these strategies, the healthcare system can better support caregivers and provide optimal care for children with IBD.

Limitation

Therearesome limitations of this study. First, since the complete control strategy was released on January 8, 2022, when our data were obtained, the number of affected persons has gradually decreased, with the majority of them in the recovery stage, and the burden on all types of burdens may be underestimated.Another limitation of the survey is that it was distributed online, which may have excluded caregivers who do not have reliable internet access or are unfamiliar with online platforms and result in a sample bias.In addition, the fact that there was a disparity between the numbers of infected and uninfected individuals makes it necessary to balance the sample sizes for the two groups, which might introduce bias. Besides, the survey used in this study was not formally validated, which may have led to reduced reliability and accuracy of the study findings.

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