


# Psychosocial Adaptation Among Inflammatory Bowel Disease Patients and Associated Factors: A Cross-Sectional Study

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**Purpose:** Patients with inflammatory bowel disease (IBD) suffer from physical symptoms and psychosocial issues. This generates risks of psychosocial maladjustment that is closely linked with self-care ability and health-related quality of life. The study aimed to explore psychosocial adaptation of IBD patients in China and the influencing factors from individual and family levels.

**Patients and Methods:** Using a cross-sectional design, 191 Chinese patients with IBD were recruited from October 2020 to September 2021. General information questionnaire, general family functioning scale, resilience scale for IBD, and psychosocial adaptation questionnaire for IBD were used for investigation. Multivariate linear regression was used to identify predictive factors of psychosocial adaptation.

**Results:** IBD patients reported a moderate level of psychosocial adaptation. Regression analysis showed that personal resilience especially the three dimensions (i.e., positive illness perception, disease management, and support from fellow IBD patients), general family functioning, and disease conditions (i.e., extra-intestinal manifestations and current disease status) were the main contributing factors of psychosocial adaptation, explaining 49.3% of the total variance.

**Conclusion:** The findings suggest that healthcare providers could focus on improving patients' illness perception about IBD and strengthening their disease management abilities, together with optimizing patients' family functioning to enhance their psychosocial adaptation level.

**Keywords:** inflammatory bowel disease, psychosocial adaptation, family functioning, resilience

## Introduction

Inflammatory bowel disease (IBD) is a group of chronic intestinal inflammatory and immune-mediated disorders with undefined etiology, including two main types, i.e., ulcerative colitis (UC) and Crohn's disease (CD).<sup>1</sup> Globally, the incidence of IBD has increased over the past few decades.<sup>2</sup> In the period 2020–2050, most Western countries are in the stage of the compounding prevalence in which incidence is stable and prevalence is rising dramatically.<sup>3</sup> However, newly industrialized countries including China are in the stage of acceleration in incidence. Over the last decade, the number of individuals diagnosed with IBD has been expanding rapidly with the rising incidence in China due to the improvement of medical technology (e.g., colonoscopy) and lifestyle changes (e.g., Westernized diet) among the Chinese population.<sup>4</sup> By 2025, the number of IBD patients in China is expected to reach over 1.5 million.<sup>5</sup>

The clinical manifestations of IBD include mucopurulent bloody stool, abdominal pain, persistent diarrhea, weight loss, and extra-intestinal manifestations (e.g., aphthous stomatitis, uveitis, and arthritis).<sup>1,6</sup> In some cases, patients may have complications including intestinal volvulus, intestinal perforation, or even the possibility of cancer. These symptoms can disrupt patients' goals, social and daily functioning, and thus adversely impact patients' psychological and social well-being.<sup>7</sup>

At present, IBD is incurable and is characterized by alternating periods of relapse and remission.<sup>8</sup> Available treatments are designed to control and manage inflammation through diet and medication.<sup>9</sup> Drugs commonly used by IBD patients include immunosuppressants and hormones. These drugs cause some side effects such as increased risk of infection and impaired body image (e.g., obesity and moon face), which in turn increases the psychological burden and difficulty of adherence to treatment of patients.<sup>10</sup>

Both the physiological symptoms and treatment regimens render patients vulnerable to various psychosocial issues.<sup>6,11</sup> Studies found that a third of patients reported anxiety symptoms and a quarter suffered depressive symptoms, which evinces a higher prevalence of anxiety and depression among IBD patients than the general population.<sup>12,13</sup> In addition, 78% of IBD patients had sleep disorders such as prolonged time to fall asleep, increased number of nocturnal awakenings, and shortened sleep duration.<sup>14</sup> IBD patients were negatively affected in self-efficacy and social participation to varying degrees by the disease.<sup>6,15</sup> These findings suggested that the psychological and social issues of IBD patients are worthy of attention by healthcare providers during IBD care.

Psychosocial adaptation to illness refers to patients' emotional experience, self-evaluation and attitude after illness, as well as the process of adjusting behaviors to various social groups and norms.<sup>16</sup> A growing body of literature has demonstrated that improving patients' psychosocial adaptation was an effective strategy to alleviate psychological distress and improve patients' quality of life in various chronic care contexts (e.g., diabetes and kidney disease).<sup>17,18</sup> Despite an increasing incidence of IBD in China, the psychosocial adaptation of IBD patients and the associated factors were less explored.

Studies showed that resilience, family functioning and psychosocial adaptation were closely related among patients with chronic diseases.<sup>19–21</sup> Resilience had the potential to buffer stress caused by chronic diseases and maintain patients' physical and emotional well-being.<sup>22</sup> Resilience had a significantly positive effect on mental health-related quality of life.<sup>23</sup> Specifically, a higher level of resilience predicted a greater level of adaptation among IBD patients,<sup>24</sup> while a lower level of resilience was associated with higher levels of anxiety and depression.<sup>25</sup> In addition, family variables were often considered in pediatric IBD research. A recent review reveals a consistent relationship between certain family functioning domains (e.g., problem-solving and communication) and children psychosocial functioning.<sup>26</sup> This review also indicates that culture needs to be taken into account regarding the conclusion about the role of family functioning in pediatric IBD because the majority of available studies were conducted in the United States with predominantly Caucasian samples.<sup>26</sup> Besides, research from other countries reported that sociodemographic and disease-related factors were closely associated with psychosocial aspects of IBD patients. For instance, an Irish study demonstrated that education and occupational status were predictors of psychological adaptation, quality of life, and functional independence in IBD patients.<sup>27</sup>

The above studies provided insights into the associated factors of psychosocial adaptation in IBD patients. However, previous studies on this topic mainly focused on influencing factors at a certain level, and few studies addressed the joint impact of these factors at different levels on the psychosocial adaptation of IBD patients, especially in China, where IBD is a relatively new disease. This study aims to investigate the level of psychosocial adaptation of IBD patients, with consideration of factors from personal resilience, family functioning, sociodemographic and disease features.

## Patients and Methods

### Study Design and Setting

A cross-sectional research design was used, following the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) statement. The study was conducted at a tertiary public hospital in Qingdao, which has an IBD specialist outpatient clinic. A questionnaire survey was conducted among patients who were admitted to the IBD clinic or the gastroenterology department between October 2020 and September 2021.

### Participants

Patients with IBD were recruited via convenience sampling. The inclusion criteria were (1) aged  $\geq 18$  years; (2) diagnosed with IBD (according to Chinese consensus on IBD diagnosis and treatment);<sup>28</sup> (3) able to read and understand the questionnaire; and (4) willing to participate in the study. The exclusion criteria were (1) with mental, intellectual or speech dysfunction; and (2) accompanied by other serious diseases. In total, 211 IBD patients met the criteria. After the

exclusion of 20 patients due to missing or incomplete responses, data of 191 IBD patients were retained for final analyses, resulting in an effective response rate of 90.52%.

## Measures

### General Information Questionnaire

This questionnaire was designed by the research team, including the patient's age, gender, marital status, education level, occupational status, annual household income, medical payment methods, disease duration, disease status, times of hospitalization, extra-intestinal manifestation and comorbidity.

### General Family Functioning Scale (GFF)

The GFF was developed by Chinese scholars<sup>29</sup> to evaluate the general function of the family. There were 9 items in total, with each item being rated on a 4-point Likert scale from "1= strongly disagree" to "4= strongly agree". The score of GFF ranges from 9 to 36, with a higher score indicating better function. The Cronbach's  $\alpha$  of GFF in the present study was 0.76.

### Resilience Scale for Inflammatory Bowel Disease (RS-IBD)

The RS-IBD was developed by Luo<sup>30</sup> with acceptable reliability and validity to specifically measure the resilience level of IBD patients, including 6 dimensions of disease management (4 items), proactive response to difficulties (6 items), positive illness perception (5 items), emotional regulation (4 items), family support (3 items) and support from fellow IBD patients (3 items). There were 25 items in total, with each item being rated on a 5-point Likert scale from "1= never" to "5= always". The total score is 25 to 125, with higher scores signifying better resilience. The Cronbach's  $\alpha$  of RS-IBD was 0.95 in the present study.

### Psychosocial Adaptation Questionnaire for IBD Patients

The psychosocial adaptation questionnaire was developed by Chinese scholars<sup>16</sup> with good reliability and validity to specifically measure the psychosocial adaptation of IBD patients. It includes 6 dimensions of anxiety/depression (10 items), sleep disorder (4 items), self-efficacy (5 items), body image (3 items), social support (3 items) and attitude (4 items). There were 29 items in total, with each item being rated on a 5-point Likert scale from "1= never" to "5= always". The total possible scores ranged from 29 to 145 (<101 implying low level of adaptation; 101–120 implying medium level; and >120 implying high level). The Cronbach's  $\alpha$  of the questionnaire was 0.88 in the present study.

## Data Collection

The data were collected in a combination of paper questionnaires and electronic questionnaires. Paper questionnaires were distributed by the investigators to IBD patients who met inclusion criteria. Before the investigation, the investigators explained the study aims and ethical principles to the participants. Participants filled in the questionnaires after signing informed consent. All paper questionnaires were returned on site. The investigators checked questionnaires in terms of completeness and asked the participants to fill out missing items on site. In addition, with the consent of the director and the head nurse of the gastroenterology department, electronic questionnaires were distributed in the WeChat (the most popular social media app in China) group of IBD patients. Similar with paper questionnaire, the purpose, method of filling out the questionnaires and ethical principles were attached in the electronic questionnaire. To avoid repeated filling, the electronic questionnaire was set up to allow one WeChat account logging in for only one time, and can only be submitted when participants completed all the items. Each questionnaire took around 15–20 minutes to complete.

## Data Analyses

All data analyses were performed using IBM Statistical Package for Social Sciences (SPSS) for Windows, version 26.0. Categorical variables were expressed by frequency and percentage, and continuous variables were presented by mean and standard deviation. The relationship among general family functioning, resilience and psychosocial adaptation was analyzed by Pearson correlation analysis. Due to the normal distribution of the dependent variable, differences across

groups were assessed using independent-samples *t* test or one-way analysis of variance. Multivariate step-by-step linear regression analysis was used to identify factors associated with psychosocial adaptation. In Step 1, the sociodemographic and clinical variables that were significant in the univariate analysis were included as an initial model. In Step 2, resilience and family functioning were introduced into the model. Multicollinearity test was performed on the data before linear regression. Both the variance inflation factors (VIF) ( $\leq 2.27$ ) and tolerance statistics ( $\geq 0.44$ ) met the cut-off points of less than 10 and greater than 0.10, respectively, indicating that independent variables can be reasonably entered into multivariate analysis. Statistical significance was determined by a *p*-value  $< 0.05$ .

## Ethical Considerations

The study complied with the Declaration of Helsinki and was approved by the Ethics Committee of Medical College of Qingdao University (approval NO: QDU-HEC-2021158). All the participants signed informed consent.

## Results

### General Characteristics

A total of 191 IBD patients effectively completed the questionnaire. They were aged 18–81 years (mean age  $44.47 \pm 13.35$ ), with 76 females (39.79%) and 115 males (60.21%). Most of the participants were diagnosed with UC (91.62%) and a few (8.38%) were diagnosed with CD. The majority of the participants was married (84.29%) and used urban resident medical insurance (67.54%) to pay medical expenses. The median duration of IBD among the participants was 3 years. Overall, 60.2% of the participants were in disease remission state, and 77.5% did not have extra-intestinal manifestations. Other characteristics of the sample are shown in Table 1.

### Scores of General Family Functioning, Resilience and Psychosocial Adaptation in IBD Patients

The general family functioning (GFF) score of participants was  $27.04 \pm 3.74$ , and the overall resilience (RS-IBD) score was  $73.42 \pm 16.69$ . Among the six dimensions of RS-IBD, the highest score was family support followed by disease management, positive illness perception, emotional regulation, proactive response to difficulties, and support from fellow IBD patients. The total score of psychosocial adaptation questionnaire was  $111.16 \pm 15.54$ , with the highest score in the dimension of body image, followed by dimensions of anxiety/depression, self-efficacy, sleep disorder, attitude, and social support. The scores of each dimension in RS-IBD and psychosocial adaptation questionnaire are shown in Table 2.

### The Correlation Between Psychosocial Adaptation, Resilience and General Family Functioning

The total score of psychosocial adaptation was significantly and positively correlated with the overall resilience score and its dimensions except the dimension of support from fellow IBD patients (*r* ranged from 0.363 to 0.575,  $p < 0.01$ ). The dimensions of psychosocial adaptation except sleep disorder were also positively related with the overall resilience score (*r* ranged from 0.288 to 0.525,  $p < 0.01$ ). The total score of psychosocial adaptation and scores of all dimensions were significantly and positively correlated with the general family functioning score (*r* ranged from 0.182 to 0.432,  $p < 0.05$ ). More details are presented in Table 3.

### Analysis of Factors Influencing Psychosocial Adaptation

The univariate analysis was used to analyze the impact of participants' demographics on psychosocial adaptation. The results showed that there was a statistical significance among groups of participants in psychosocial adaptation by current disease status ( $t = 2.879$ ,  $p < 0.01$ ) and having extra-intestinal manifestations or not ( $t = 3.509$ ,  $p < 0.01$ ). However, demographic and other disease characteristics did not show significant difference. The statistical analysis results are shown in Table 1.

Multivariate stepwise linear regression analysis was performed to identify the predictive factors of psychosocial adaptation. With the total score of psychosocial adaptation as the dependent variable, current disease status, having extra-intestinal

**Table 1** Demographic and Disease Characteristics and Univariate Analysis of Factors Influencing Psychological Adaptation of Participants (n=191)

Variables	Categories	Frequency	Percentage (%)	Total Score of Psychosocial Adaptation	t/F	P
Gender	Male	115	60.21	110.23±15.86	-1.019	0.310
	Female	76	39.79	112.57±15.03		
Age (year)	18~44	98	51.31	108.65±16.79	2.670	0.072
	45~59	69	36.13	113.93±13.50		
	≥60	24	12.56	113.42±14.49		
BMI (kg/m <sup>2</sup> )	<18.5	23	12.04	109.48±14.80	0.838	0.475
	18.5~24	112	58.64	112.08±15.32		
	24~28	41	21.47	111.56±15.92		
	≥28	15	7.85	105.73±17.46		
Education level	Primary school and below	10	5.23	110.70±15.45	0.442	0.778
	Secondary school	52	27.23	111.77±15.14		
	Senior high school or equivalent	50	26.18	110.74±17.05		
	Junior college	28	14.66	108.04±15.87		
	Bachelor degree and above	51	26.70	112.75±14.53		
Marital status	Unmarried	28	14.66	111.14±14.59	0.987	0.375
	Married	161	84.29	110.97±15.74		
	Divorced	2	1.05	126.50±0.71		
Permanent address	Urban area	138	72.25	111.20±15.96	0.055	0.956
	Rural area	53	27.75	111.06±14.51		
Living arrangement	Live alone	11	5.76	105.36±15.83	0.939	0.393
	Live with family	173	90.58	111.39±15.67		
	Live at school or work dormitory	7	3.66	114.43±10.68		
Occupational status	Full-time job	144	75.40	110.94±15.59	0.385	0.681
	Part-time job	4	2.09	105.75±14.03		
	Unemployment	43	22.51	112.37±15.69		
Annual household income (Yuan)	<30,000	36	18.85	109.00±16.08	1.300	0.272
	30,000~49,999	47	24.61	108.79±16.44		
	50,000~100,000	61	31.93	111.97±15.63		
	>100,000	47	24.61	113.68±13.76		
Medical payment	Self-paying	20	10.47	110.55±18.81	0.017	0.983
	Rural cooperative medical	42	21.99	111.24±14.54		
	Urban resident medical insurance	129	67.54	111.22±15.43		

(Continued)

**Table 1** (Continued).

Variables	Categories	Frequency	Percentage (%)	Total Score of Psychosocial Adaptation	t/F	P
Duration of disease (year)	<1	27	14.14	111.96±14.18	0.029	0.993
	1~4	97	50.78	110.96±16.38		
	5~9	34	17.80	111.12±17.39		
	≥10	33	17.28	111.12±12.34		
Times of hospitalization	<5	159	83.25	111.86±15.55	1.388	0.167
	≥5	32	16.75	107.69±15.25		
Current disease status	Remission stage	115	61.21	113.74±14.09	2.879	0.004
	Active stage	76	39.79	107.25±16.85		
Extra-intestinal manifestations	Yes	43	22.51	104.05±15.21	3.509	0.001
	No	148	77.49	113.22±15.06		
Comorbidity	Yes	49	25.65	108.96±16.70	1.149	0.252
	No	142	74.50	111.92±15.10		

**Table 2** Scores of Resilience, Psychosocial Adaptation and General Family Functioning of Participants (n=191)

Variables	Score Range	Actual Score ( $\bar{x} \pm s$ )	Average Score of Items ( $\bar{x} \pm s$ )	Rank
RS-IBD	27~100	73.42±16.69	2.94±0.67	
Family support	2~12	10.04±2.34	3.35±0.78	1
Disease management	5~16	12.83±2.55	3.21±0.64	2
Positive illness perception	4~20	15.26±4.03	3.05±0.81	3
Emotional regulation	1~16	11.82±3.24	2.96±0.81	4
Proactive response to difficulties	3~24	16.73±4.91	2.79±0.82	5
Support from fellow IBD patients	0~12	6.73±3.52	2.24±1.17	6
Psychosocial adaptation questionnaire	70~144	111.16±15.54	3.83±0.54	
Body image	5~15	13.53±2.09	4.51±0.70	1
Anxiety/depression	17~50	40.53±7.59	4.05±0.76	2
Self-efficacy	5~25	19.18±3.86	3.84±0.77	3
Sleep disorder	5~20	14.40±3.23	3.60±0.81	4
Attitude	4~20	13.74±3.41	3.43±0.85	5
Social support	3~15	9.78±3.39	3.26±1.13	6
GFF	16~36	27.04±3.74	3.00±0.42	

**Abbreviations:** RS-IBD, Resilience Scale for Inflammatory Bowel Disease; GFF, General Family Functioning Scale.

**Table 3** Correlations Between Resilience, General Family Functioning and Psychosocial Adaptation in Participants (n=191)

Variables	Psychosocial Adaptation	Anxiety/Depression	Sleep Disorder	Self-Efficacy	Body Image	Social Support	Attitude
RS-IBD	0.533 <sup>b</sup>	0.316 <sup>b</sup>	0.08	0.525 <sup>b</sup>	0.288 <sup>b</sup>	0.418 <sup>b</sup>	0.461 <sup>b</sup>
Disease management	0.504 <sup>b</sup>	0.335 <sup>b</sup>	0.139	0.498 <sup>b</sup>	0.342 <sup>b</sup>	0.227 <sup>b</sup>	0.416 <sup>b</sup>
Proactive response to difficulties	0.494 <sup>b</sup>	0.299 <sup>b</sup>	0.106	0.530 <sup>b</sup>	0.286 <sup>b</sup>	0.289 <sup>b</sup>	0.420 <sup>b</sup>
Positive illness perception	0.575 <sup>b</sup>	0.434 <sup>b</sup>	0.156 <sup>a</sup>	0.390 <sup>b</sup>	0.329 <sup>b</sup>	0.370 <sup>b</sup>	0.493 <sup>b</sup>
Emotional regulation	0.487 <sup>b</sup>	0.325 <sup>b</sup>	0.059	0.504 <sup>b</sup>	0.262 <sup>b</sup>	0.297 <sup>b</sup>	0.412 <sup>b</sup>
Family support	0.363 <sup>b</sup>	0.234 <sup>b</sup>	0.159 <sup>a</sup>	0.206 <sup>b</sup>	0.282 <sup>b</sup>	0.347 <sup>b</sup>	0.230 <sup>b</sup>
Support from fellow IBD patients	0.126	-0.113	-0.210 <sup>b</sup>	0.345 <sup>b</sup>	-0.086	0.484 <sup>b</sup>	0.206 <sup>b</sup>
GFF	0.432 <sup>b</sup>	0.275 <sup>b</sup>	0.298 <sup>b</sup>	0.182 <sup>a</sup>	0.294 <sup>b</sup>	0.298 <sup>b</sup>	0.391 <sup>b</sup>

Notes: <sup>a</sup>p<0.05; <sup>b</sup>p<0.01.

Abbreviations: RS-IBD, Resilience Scale for Inflammatory Bowel Disease; GFF, General Family Functioning Scale.

**Table 4** Multivariate Linear Regression Analyses of Predictors of Psychosocial Adaptation in Participants

	Unstandardized Regression Coefficient (B)	Standard Error	Standardized Regression Coefficient ( $\beta$ )	t-value	P-value
Constant	45.539	6.956		6.547	<0.001
Positive illness perception	1.700	0.301	0.440	5.656	<0.001
GFF	1.190	0.227	0.286	5.245	<0.001
Disease management	1.218	0.450	0.200	2.709	0.007
Support from fellow IBD patients	-0.829	0.272	-0.188	-3.043	0.003
Extra-intestinal manifestations	-4.684	2.003	-0.126	-2.338	0.020
Current disease status	-3.747	1.689	-0.118	-2.219	0.028

Notes:  $R = 0.714$ ,  $R^2 = 0.509$ , Adjusted  $R^2 = 0.493$ ,  $F = 31.842$ ,  $P < 0.001$ .

Abbreviation: GFF, General Family Functioning Scale.

manifestations or not, all dimensions of resilience, and general family functioning were taken as independent variables. The results showed that positive illness perception in resilience scale ( $\beta = 0.440$ ) was the most significant contributing factor of psychological adaptation, followed by general family functioning ( $\beta = 0.286$ ), disease management in resilience scale ( $\beta = 0.200$ ), support from fellow IBD patients in resilience scale ( $\beta = -0.188$ ), extra-intestinal manifestations ( $\beta = -0.126$ ) and current disease status ( $\beta = -0.118$ ), together explaining 49.3% of the total variance. The specific results are presented in Table 4.

## Discussion

IBD patients had a moderate level of overall psychosocial adaptation. Patients in remission state reported higher levels of psychosocial adaptation than those at active stage in this study. Research reported that IBD patients at active stage had more obsessive-compulsive symptoms, such as diarrhea and abdominal pain.<sup>31</sup> These unpredictable clinical manifestations made them experience high levels of psychological stress.<sup>31</sup> This finding indicates that psychosocial adaptation is not static, but could be in a dynamic process for individual IBD patients. Therefore, longitudinal studies can be designed in future to capture the patterns or trajectories of psychosocial adaptation in IBD patients.



Our study also found that patients without extra-intestinal manifestations had higher psychosocial adaptation scores than those with extra-intestinal manifestations. The inflammation of IBD mainly affects the gut, but also generates abnormal responses of other tissues and organs including eyes (e.g., uveitis), joints (e.g., spondyloarthritis), skin (e.g., erythema nodosum), and hepatobiliary tract (e.g., cholangitis).<sup>1</sup> Notably, the extra-intestinal manifestations were found to be associated with more severe negative emotions (e.g., anxiety and depression) among IBD patients.<sup>32</sup> Simultaneously, the presence of extra-intestinal manifestations was related to lower social function of patients compared to the absence of extra-intestinal manifestations.<sup>33</sup> In addition, both current disease status and extra-intestinal manifestations were included in the multivariate regression model. Therefore, disease severity was a significant factor of psychosocial adaptation among IBD patients. These findings highlight the complex inter-related biopsychosocial aspects of IBD.<sup>34</sup> Accordingly, healthcare professionals need to timely identify patients' extra-intestinal manifestations, and pay particular attention to the mental state and behavioral responses of patients in active state and those with extra-intestinal manifestations. In the mean time, relevant health education and intervention programs need to be formulated and tailored for patients in different disease states. These efforts may help IBD patients manage the disease, and ultimately well adapt to the disease.

Unlike disease variables, demographic variables in the present study did not show influence on psychosocial adaptation among IBD patients. This finding is inconsistent with previous research.<sup>27</sup> The difference may be attributed to the convenience sampling method used in the present study. Further study thus is needed to validate the influence of demographics on psychosocial adaptation of IBD patients.

In this study, except the dimension of sleep disorder in psychosocial adaptation questionnaire, the other five dimensions of anxiety/depression, self-efficacy, body image, social support and attitude were significantly and positively correlated with the overall resilience score and its five dimensions (i.e., disease management, proactive response to difficulties, positive illness perception, emotional regulation and family support). In addition, the level of psychosocial adaptation and its six dimensions showed a positive correlation with general family functioning. In other words, patients with higher resilience and better general family functioning had a greater level of psychosocial adaptation.

Furthermore, the results of multivariate regression analysis showed that positive illness perception, disease management, support from fellow IBD patients in the resilience scale and general family functioning were the major contributing factors of psychosocial adaptation after controlling for disease-related variables. Specifically, higher scores of positive illness perception, disease management, and general family functioning promote better psychosocial adaptation of IBD patients. Notably, positive illness perception was the strongest predictor of psychosocial adaptation. A previous study in Ireland similarly found poorer psychological adaptation among individuals who tended to attribute a wide range of symptoms to IBD and believed in their IBD having serious consequences.<sup>27</sup> IBD patients who understood their condition better were less likely to report psychological distress. IBD patients perceiving their disease as understandable and controllable showed more active coping behaviors.<sup>27</sup> Better coping enables individuals to manifest resilience and thrive in the areas of life satisfaction and personal growth, and thus exhibit a higher level of adaptation.<sup>35</sup> These findings help uncover the mechanism underlying the influence of positive illness perception on psychosocial adaptation of IBD patients. This highlights the need for illness perception intervention programs, in which healthcare professionals provide patients with clear and detailed information about IBD, and thus support patients to establish positive perception of the disease to promote their psychosocial adaptation.

Followed by positive illness perception, family functioning was the second most significant predictive factor of psychosocial adaptation among IBD patients, which is similar to findings among epilepsy patients.<sup>19</sup> Effective family functioning means that family members including the one with disease are capable to maintain cohesive relationships, effectively communicate with each other, alter family routines to adjust to a stressor (e.g., illness), fulfill family roles, and cope with family problems, which are thus conducive to psychosocial adaptation for individuals with disease.<sup>36</sup> In addition, family functioning differs by cultural influence for families with patients.<sup>37</sup> In Chinese context deeply influenced by Confucianism, family is attached great importance in terms of providing care and support for members with disease.<sup>38</sup> In the present study, participants reported a moderate level of family functioning, which contributed to their moderate level of psychosocial adaptation. In general, good family functioning predicts desirable psychosocial health outcomes.<sup>36</sup> Accordingly, family functioning needs to be taken into consideration to promote patients' psychosocial adaptation for optimizing IBD care. Effective strategies targeting on family functioning such as supporting family



to identify strengths and resources of family, and applying a multidisciplinary approach (e.g., collaborating with social workers, psychologists and family therapists)<sup>36</sup> could be drawn on to promote IBD patients' family functioning.

The present study also found psychosocial adaptation increased with the rising level of disease management among IBD patients. Literature suggests that nonadherence is a common difficulty in disease management among IBD patients, which may lead to increased disease activity and impaired psychosocial functioning.<sup>39</sup> There is evidence that promoting patients' disease management can improve their treatment compliance, thereby contributing to improved disease outcomes and disease adaptation levels.<sup>40</sup> For this reason, healthcare professionals including nurses could focus on improving patients' disease management ability (e.g., in aspects of diet and medication) as a part of the intervention strategies to enhance patients' psychosocial adaptation.

Distinctively, the present study showed that support from fellow IBD patients negatively affected the psychosocial adaptation of IBD patients, which differs from previous research. In studies on other chronic diseases (e.g., diabetes, chronic obstructive pulmonary disease), support from fellow patients has been found to help patients increase their ability to adapt to the illness and improve their health-related quality of life.<sup>41,42</sup> However, a qualitative study in Germany reported negative effects of social support on IBD patients.<sup>43</sup> Participants in this study described that in support groups, they tended to compare who was more successful in dealing with the condition, leading to competition and anxiety rather than emotional support for those in a worse condition. In light of this finding, the role of support from fellow IBD patients need to be further explored to uncover its influence on psychosocial adaptation in Chinese context.

In addition, participants in the present study reported lowest score of support from fellow IBD patients dimension in the resilience scale and lowest score of social support dimension in the psychosocial adaptation questionnaire, indicating that they received little social support. One possible reason for this finding may be attributed to the influence of stigma, which leads to self-blame and avoidance.<sup>44</sup> Data showed that stigma was highly prevalent among IBD patients (up to 84%) due to lack of public awareness and knowledge about IBD.<sup>45</sup> Patients considered IBD to be more stigmatizing than other stigmatized diseases (e.g., AIDS and cancer), especially among young patients.<sup>45</sup> In the present study, most of the participants (87.44%) were middle-aged and young adults. Due to stigma, IBD patients sometimes engaged in self-isolating behaviors rather than disclosing the disease to others, which generated psychological distress (e.g., anxiety, depression) and decreased medication adherence, ultimately impacting their psychosocial adaptation.<sup>44</sup> These findings further suggest that sources of social support require particular attention for IBD patients in terms of the possible reverse direction of effect.

In fact, in current Chinese healthcare settings, a growing number of health interventions and health education are designed based on online support from fellow patients,<sup>46</sup> which could compensate time and space barriers to face-to-face interaction between health professionals and patients. However, uncertainty and anxiety may arise for patients due to conflicting information disseminated by fellow IBD patients.<sup>43,46</sup> This fact may also account for the negative effects of support from fellow patients on psychosocial adaptation among the participants in the present study. In view of the above situation, healthcare professionals need to clarify the possible negative effects of support from fellow patients and help IBD patients to access scientific and reliable information from online resources like the China Crohn's & Colitis Foundation.

## Limitations and Future Directions

This study has several limitations. First, the participants were selected using convenience sampling with a relatively small sample size, which results in limited generalization of the results to all IBD patients. Second, due to the cross-sectional design, the dynamics of psychosocial adaptation with disease progression cannot be captured and the causality between study variables cannot be determined. Finally, this study only analyzed the impacts of the demographic and disease characteristics, resilience, and general family functioning of IBD patients on psychosocial adaptation. More cognitive factors such as coping and illness acceptance as revealed by previous research<sup>35</sup> could be included to further examine the influencing factors of psychosocial adaptation. An ecological model can be drawn on in future to further analyze factors in what ecological systems contribute most to the psychosocial adaptation of IBD patients.<sup>47</sup>

## Conclusion

The psychosocial adaptation of IBD patients was at a moderate level. Positive illness perception, general family functioning, disease management, support from fellow IBD patients, having extra-intestinal manifestations or not, and

current disease status are the most significant factors influencing psychosocial adaptation. When providing care for IBD patients, healthcare professionals including nurses need to regularly assess psychosocial status, paying particular attention to patients with extra-intestinal manifestations and those in disease active state. In order to improve patients' psychosocial adaptation level, healthcare professionals could develop related intervention programs to help patients positively understand IBD, improve family functioning and effectively manage IBD, with consideration of the negative effect of support from fellow IBD patients on psychosocial adaptation.

## Data Sharing Statement

The data that support the findings of this study are available from the corresponding authors upon reasonable request.

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## Disclosure

The authors report no conflicts of interest in this work.

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