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RESEARCH ARTICLE

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Factors promoting and hindering resilience in youth with inflammatory bowel disease: A descriptive qualitative study

Lili You[1] | Siyao Wang[1] | Yangyang Wang[2] | Lingling Zhu[2] | Tiantian Wang[1] | Xiang Yu[1] | Jing Dong[1] | Yuxia Guan[3]

[1]Department of Gastroenterology, Peking Union Medical College Hospital, Beijing, China

[2]Nursing Department, Peking Union Medical College Hospital, Beijing, China

[3]Department of Internal Medicine, Peking Union Medical College Hospital, Beijing, China

Correspondence
Yuxia Guan, Department of Internal Medicine, Peking Union Medical College Hospital, Beijing 100730, China.
Email: guanyuxiatougao@88.com

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Abstract

Aim: To explore factors promoting and hindering resilience in youth with inflammatory bowel disease (IBD) based on Kumpfer's resilience framework.

Design: A descriptive qualitative study design with an interpretative approach was used.

Methods: Participants consisted of 10 youths with IBD from a tertiary hospital in Beijing (China) recruited using the purposive sampling method. Data were collected by semi-structured interviews from December 2020 to March 2021. The directed content analysis was performed for data analysis.

Results: Both promoting factors and hindering factors could be divided into personal factors and environmental factors. Thirteen themes were identified. The promoting factors included acceptance of illness, strict self-management, previous treatment experience, life goals, family support, medical support and peer encouragement. Stigma, lack of communication, negative cognition, societal incomprehension, economic pressure and academic and employment pressure were hindering factors.

Conclusion: Health care professionals need to develop greater awareness of factors, stemming from both the individual and the outside world, that hinder or promote resilience in order to aid young patients with IBD. Building targeted nursing measures to excavate the internal positive quality of patients, provide external support and promote the development of resilience.

KEYWORDS
inflammatory bowel disease, nursing, qualitative study, resilience, youth

1 | INTRODUCTION

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and Ulcerative Colitis (UC), has been more common in Western countries historically, with a prevalence of up to 0.5% (Kaplan, 2015). With the development of economies and changes in social environments, IBD has become a global disease. The incidence rate of IBD in Asia has increased dramatically, varying from 0.58 to 3.43 per 1 million people in China (Ng et al., 2017). Approximately 20%–30% of new IBD patients are diagnosed during childhood or adolescence (Rubalcava & Gadepalli, 2021). Due to disease symptomatology, disease experience, treatment

experience and/or side effects, and the interplay between the gut, chronic inflammation, and the central nervous system, IBD has serious negative effects on adolescent health-related quality of life (HRQL), resulting in an increased risk for depression and anxiety, difficulties with social and school functioning, and attempted suicide (Butwicka et al., 2019; Halloran et al., 2020). However, some youth can live in harmony with IBD and have a better quality of life, demonstrating a high level of resilience. It is worth exploring which factors influence this preferred result.

2 | BACKGROUND

Resilience is described by the American Psychological Association (2020) as "the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress." Resilience is a complicated interaction of risk factors and protective factors that leads to positive development results. Research has indicated that high resilience is independently associated with lower disease activity and better quality of life in patients with IBD (Sehgal et al., 2021). However, people with chronic gastrointestinal diseases generally have lower levels of resilience compared to the general population (Parker et al., 2020). The question worth exploring is: which factors affect the resilience process in patients with IBD?

Previous studies have shown that nurses play an important role in improving patients' resilience by taking interventions such as function-focused care (Resnick et al., 2016), self-management education (Edward et al., 2019), and psychoeducational interventions (Wu et al., 2018). Kumpfer's resilience framework indicates that the resilience process is dynamic, in which protective and hindering factors interplay and interact (Kumpfer, 2002). Knowing the factors affecting the resilience process of young patients with IBD, nurses can take more effective targeted interventions to reduce hindering factors and increase protective factors so as to improve their resilience (Jiang et al., 2019).

Currently, there is insufficient research that explores fully the promoting and hindering factors affecting the development of resilience in young patients with IBD. Previous studies on adolescent patients with IBD primarily focused on understanding the impact of IBD on youth psychosocial health, including quality of life, well-being, social support, general stress perception, depression and anxiety symptoms (Halloran et al., 2020). There has also been qualitative literature research that explored the feelings, challenges, and unmet needs of adolescent patients with IBD (Lee et al., 2021). Recently, a study explored the specific factors that bolstered resilience in youth with IBD from healthcare providers, parents, and youth perspectives (Kohut et al., 2021). However, factors that might hinder resilience remain unclear. Therefore, based on Kumpfer's resilience framework, this study explored the promoting and hindering factors that influence the resilience of adolescent patients with IBD so as to provide a reference for clinical nursing practice.

3 | METHODS

The aim of this qualitative study was to explore and gain deeper understanding of factors that promote and hinder the resilience of youth with IBD based on Kumpfer's resilience framework. The study was conducted from an interpretivist point of view using a qualitative descriptive design with semi-structured interviews. This method, which seeks factual responses to questions about the factors that facilitate or hinder phenomena, is especially suited to health environment research (Colorafi & Evans, 2016).

3.1 | Setting

This study was undertaken in Peking Union Medical College Hospital. The hospital is designated by the National Health Commission as one of the national referral centers offering diagnostic and therapeutic care of complex and rare diseases.

3.2 | Sample/participants

From December 2020 to March 2021, participants were recruited from the gastroenterology ward of the hospital using a purposeful sampling method. Patients were included if they met the following criteria: (1) aged between 14 and 35 years (according to the age classification of youth by the relevant laws and regulations of the People's Republic of China); (2) diagnosed with IBD for at least 6 months; (3) conscious and able to communicate in Chinese; (4) willing to participate. Patients with mental disorders, cancers, or other severe diseases were excluded from the study. The sample size was determined by data saturation at the point where no new themes were found from additional participants (Trotter, 2012). Ten youths were enrolled in this study, including six patients with CD and four patients with UC. Patient demographic information of participants is shown in Table 1. The names of participants have been replaced with numbers to protect patient privacy.

3.3 | Data collection

Data were collected through in-depth, face-to-face, semi-structured interviews. Interviews were conducted in Chinese. The interview guide was developed based on Kumpfer's resilience framework and literature review. Then, two experts in clinical psychology and clinical nursing were invited to revise the guide, and a question about the future plan was added, and some expressions were modified. Finally, three pilot interviews with youth patients with IBD were conducted to assess the feasibility and comprehensibility of the interview guide, and no changes were requested. The interview guide contained nine questions (Table 2). The interviews were audio-recorded with the participants' consent and lasted for 30–60 min. The interview length was agreed upon with the interviewees in advance. The interview location, a special conversation room in the

TABLE 1 The demographic information of participants ($n = 10$).

Code	Gender	Age (years)	Educational level	Marital status	Living situation	Annual household income (10,000 yuan)	Type	Inflammatory bowel disease duration (years)	Intestinal surgery	Disease states
P1	Female	26	College or higher	Single	Alone	RMB 5–10	CD[a]	15	Yes	Remission
P2	Male	28	College or higher	Single	With family member(s)	RMB > 20	UC[b]	1	No	Active
P3	Male	27	Middle school	Single	With family member(s)	RMB < 5	CD[a]	7	Yes	Active
P4	Male	20	College or higher	Single	With friends	RMB > 20	UC[b]	3	No	Active
P5	Male	18	High school	Single	With family member(s)	RMB 10–20	CD[a]	2	Yes	Active
P6	Female	17	High school	Single	With family member(s)	RMB 10–20	CD[a]	1	No	Remission
P7	Male	17	High school	Single	With family member(s)	RMB 10–20	CD[a]	1	No	Remission
P8	Female	22	College or higher	Single	With family member(s)	RMB 10–20	UC[b]	1	No	Remission
P9	Female	28	College or higher	Single	With friends	RMB 10–20	CD[a]	2	No	Remission
P10	Male	28	College or higher	Single	Alone	RMB < 5	UC[b]	2	No	Remission

[a]CD refers to Crohn's disease.

[b]UC refers to Ulcerative Colitis.

hospital, was a quiet setting to ensure that the interview process was smooth and interviews were not disrupted. The interviews were conducted by the first author (LLY), who had a Master's degree and more than 10 years of experience in the field of IBD nursing. The interviewer adjusted the interview content flexibly according to the situation and if any, recorded participants' special non-verbal behaviour and corresponding expressions. For example, the patient cried and said, "I was too tired." All of the researchers participating in this study had received training in qualitative research. Six of the researchers had Master's degrees, and two had Bachelor's degrees.

3.4 | Data analysis

Within 24 h after each interview, the interviewer transcribed the interview recording verbatim into text. Another member of the research team checked the consistency of the text and the recordings. Then, the transcript was analysed by two other researchers line by line for emergent themes and developed a codebook in Nvivo 11 using directed content analysis based on Kumpfer's resilience framework (Elo & Kyngas, 2008), this process was called "open coding". Next, the new interview was processed in the same way as the above method, and the researchers coded the data according to the initial coding categories. If the interview data could not be categorised using the initial coding categories, the researchers assigned a new code. To maximise rigour, transcripts were coded independently by two individuals, and any discrepancies were resolved by discussion with a senior researcher.

3.5 | Validity, reliability and rigour

Some measures were taken to ensure the reliability of the study. The interviewer was trained to conduct qualitative interviews and did not have a clinical relationship with the participants prior to, or after, recruitment, as such a relationship may have had a coercive effect. The semi-structured interview guide was validated and pilot-tested. Member-checking was also performed to ensure data credibility; that is, data were returned to participants to check for accuracy and resonance with their experiences (Birt et al., 2016). To ensure confirmability, a triangulation analysis was conducted between two members of the research team. Disagreements were resolved through discussion at the research group meeting. To maintain the maximum accuracy of the original meaning, the transcripts were analysed in Chinese. The selected exemplar quotes were translated into English by a bilingual translator (Chinese–English), and another bilingual researcher verified the accuracy of the translation. The methods are reported according to the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

4 | RESULTS

The study participants ranged in age from 17 to 28 years. The factors that were found to promote and hinder the resilience of those youth with IBD can be divided into two domains: personal factors and environmental factors. Personal promoting factors included four sub-themes; environmental promoting factors included three sub-themes. Personal hindering factors and environmental hindering factors each were composed of three sub-themes (Table 3). Results are presented below, accompanied by quotes from study participants.

4.1 | Promoting factors

4.1.1 | Main theme 1: Personal promoting factors

Sub-theme 1: Acceptance of illness

Some younger youth said that they refused to accept the disease during its early stages, even taking some extreme actions to resist

TABLE 2 Main questions for the semi-structured interview.

1. Would you please share your experiences of IBD with me?
2. Can you please talk about your outlook on IBD?
3. How do you feel during the process of treatment?
4. Can you evaluate your performance in the process of treatment?
5. What impact and challenges does the disease bring to your work, study and life?
6. How do you deal with these impacts and challenges?
7. Who/What do you think gives you support in the process of treatment and disease management?
8. Do you have any plans for your future life?
9. What do you think of resilience?
10. In addition to the questions in this interview, do you have anything else to say?

Abbreviation: IBD, inflammatory bowel disease.

TABLE 3 Hindering and promoting factors of resilience in youth patients with IBD.

Theme	Sub-theme
Personal factors	Acceptance of illness
	Strict self-management
	Previous treatment experience
	Life goals
	Stigma
	Lack of communication
	Negative cognition
Environmental factors	Family support
	Medical support
	Peer encouragement
	Societal incomprehension
	Economic pressure
	Academic and employment pressure

the disease, such as refusing to eat. As time went by, subjects reported that they slowly accepted the disease and tried to live active lives. Older youth were more likely to accept the disease, face the disease calmly, and actively participate in treatment.

> When I first learned that I had this disease, I felt very uncomfortable and couldn't accept it at all. At that time, I hardly ate for 2 days. Later, I slowly accepted it, and I figured out a lot of things. After all, I was still young, and I had a long way to go. I must find a harmonious way to coexist with IBD. Only in this way could life slowly get better.
>
> (P7, 17 years old)

> I thought all things must be experienced in life. Since I had this disease, it must be a necessary process of life. As the saying goes, 'Take things as they come'. I just needed active treatment.
>
> (P2, 28 years old)

Sub-theme 2: Strict self-management

Some patients indicated that they actively sought suitable coping strategies and carried out strict self-management, which improved their sense of control over disease and life.

> I was very self-disciplined, whether it was diet or regular work and rest. As long as it could prevent the recurrence of IBD, I would do it.
>
> (P2, 28 years old)

> I kept a very regular work and rest schedule every day, got up and went to bed on time. I also strictly controlled my diet and did not eat cold and spicy foods.
>
> (P4, 20 years old)

Sub-theme 3: Previous treatment experience

Youth gained strength from previous IBD treatment experience, which helped them deal with the disease and face the difficulties and pressures in life with courage.

> I had massive bleeding several times before, but I survived. I thought I could deal with anything in the future.
>
> (P1, 26 years old)

> After experiencing the disease, I felt that I had grown a lot. Instead of avoiding difficulties as before, I would face them bravely.
>
> (P4, 20 years old)

Sub-theme 4: Life goals

Most young patients in the study believed that it was important to realize their life goals, the driving force of their lives.

> The goal was to control my illness and do something I love in the future.
>
> (P4, 20 years old)

> Most people around me had no clear goals in life. They didn't live for themselves, and their work was not to realise the value of life but for money, fame and profit.
>
> (P8, 22 years old)

4.1.2 | Main theme 2: Environmental promoting factors

Sub-theme 1: Family support

Families can provide financial support, care support and emotional support. Most youth regarded family support as the most important external support and the primary source of confidence and strength in the fight against IBD.

> My mother was optimistic, and my family loved me very much, which made me optimistic.
>
> (P5, 18 years old)

> My parents offered great support to me. They always said that they wouldn't ask a lot of me as long as I actively received treatment and my condition could be stable.
>
> (P9, 28 years old)

Sub-theme 2: Medical support

The careful and professional attitudes of doctors and nurses helped establish trust and close relationships between clinical professionals and patients. Trusting relationships reduced patients' anxiety, improved patients' treatment compliance, enhanced patients' confidence in their treatments and provided psychological support for young patients.

> The doctors and nurses were extremely professional. In addition to treating physical symptoms, they also encouraged me. I thought this was an important reason why I could stick it out during my hospitalisation. (P1, 26 years old).

> When I was admitted to the ward from the emergency department last time, although my abdomen was still very painful, I didn't worry at all when I saw the familiar doctors and nurses.
>
> (P4, 20 years old)

Sub-theme 3: Peer encouragement

Some youth said that the encouragement of other youth with IBD impacted their treatment positively. They received strength and confidence from other youth experiencing similar challenges.

I met some friends when I was in the hospital. We encouraged each other and made progress together. It made me feel like I was not alone in the fight against IBD.

(P1, 26 years old)

4.2 | Hindering factors

4.2.1 | Main theme 1: Personal hindering factors

Sub-theme 1: Stigma

Some young patients needed a nasal feeding tube. They reported believing that people considered them unlike others. They worried that a stigma associated with the feeding tube would affect their self-esteem and lead to adverse emotions such as anxiety.

Others would think I had a terminal disease because I had a nasal feeding tube and a nutrition pump. Sometimes, they were afraid that I would infect them. I haven't been out since having a nasal feeding tube, with this thing, it's... um...too difficult. [The patient stopped saying and pointed to the feeding tube].

(P8, 22 years old)

Sub-theme 2: Lack of communication

Many youth were not good at expressing their feelings to family and friends. They refused to communicate and chose to digest all stress and negative emotions by themselves because they thought others could not understand them.

I was not good at expressing my feelings, and neither were my parents. I didn't know what to say and how to say it, so I seldom communicated with them, even when I was particularly uncomfortable.

(P3, 27 years old)

Few people could understand, and I didn't like communicating with others.

(P7, 17 years old)

Sub-theme 3: Negative cognition

Some young patients thought their lives were 'abnormal'. Negative thoughts about the disease led them to pay too much attention to the limitations and adverse effects of IBD on life, thus losing confidence in treatment and hope in life.

Would the disease bring me benefits [asked in a rhetorical tone]? I didn't think so.

(P3, 27 years old)

It was a chronic disease that could not be cured. I was very depressed and sad. I got this disease at such a young age, and I might have an operation in the future. I felt there was no hope in life.

(P3, 27 years old)

I liked sports very much. Just wanting to return to the normal life before, I began to secretly eat chocolate and drink rice soup until I wanted to vomit. When the disease relapsed, I almost gave up pursuing a normal life. There was no reason to study hard and perform well on exams because I believed that even if I did well, I would not be able to live a normal life.

(P4, 20 years old)

4.2.2 | Main theme 2: Environmental hindering factors

Sub-theme 1: Societal incomprehension

Inflammatory bowel disease occurs in the intestine. Most patients do not have obvious external symptoms. Young patients indicated that it was difficult for others to understand them as a result. There were even people who misunderstood them.

When I went back to school, some classmates thought that I pretended to be ill before. The teacher hadn't had this disease, so he didn't understand me.

(P5, 18 years old)

My parents couldn't understand the disease. They always thought that I didn't listen to the doctors and caused the recurrence of IBD. It was no use explaining to them, so we often quarrelled.

(P10, 28 years old)

Sub-theme 2: Economic pressure

Long-term treatment left young patients and their families to face a heavy economic burden. Adolescent patients could only rely on their families to provide financial support, which would make them feel guilty and pressured psychologically.

We have borrowed money from all of my relatives and friends. I feel very sorry for my mother because I can only rely on her. She is too tired. [The patient cried as he spoke].

(P3, 27 years old)

The more serious the illness, the more it costs each year. Even if the disease was well controlled, it would cost RMB 20 thousand to 30 thousand yuan a year. If it was serious, it would cost more than RMB 100 thousand yuan a year. I can't always rely on my family. I knew I had to live by myself in the future.

(P8, 22 years old)

Sub-theme 3: Academic and employment pressure

In the interview, most youths said that they would frequently ask for leave or even suspend their attendance from school because of repeated illness. Having IBD not only aggravated the academic pressure on these patients but also made them feel confused and anxious about their future career choices.

> I was suspended from school because of medical treatment. Although I studied at home, I was still worried that I wouldn't catch up with my classmates when I went back to school.
>
> (P6, 17 years old)

> With this disease, I couldn't stay up late and had to ask for leave often. What can I do in the future? I feel like I have no choice.
>
> (P8, 22 years old)

5 | DISCUSSION

Studies have shown that youth with IBD have lower quality of life and higher rates of depression and anxiety than those with other chronic diseases, which adds additional challenges to youth in the development period in which they are trying to become independent and construct self-identity (Greenley et al., 2010; Halloran et al., 2020). Taking nursing interventions to improve the resilience of adolescent patients may help them have better-coping mechanisms that can buffer against the pressures related to IBD. However, previous studies lacked the exploration of the influencing factors of resilience in IBD patients, so as to lack of targeted nursing measures. This study explored the influencing factors on resilience from the perspective of youth patients with IBD. The promoting factors and hindering factors that were reported could be divided into personal and environmental domains. This study would be an addition to the existing IBD literature, which added new insight into the research on youth patients with IBD and nurse practice.

With regard to the personal domain, we found that acceptance of IBD was a promoting factor of resilience in young patients with IBD, while negative illness cognition was a hindering factor. These results align with the findings of Lee et al. who demonstrated that acceptance, a subcategory of illness cognition, was associated with resilience and quality of life in adolescents and young adults who were leukaemia survivors (Lee et al., 2019). Existing psychology research has also shown that if a person can learn to reconstruct his or her cognition of the event, interpret the situation positively, and reduce the evaluation of the negative effects after a traumatic event, he/she will be able to accept and recover in some sense (Iacoviello & Charney, 2014). IBD is an incurable and recurrent disease, which may become a persistent source of trauma and stress for young patients. By accepting IBD and developing positive illness cognition, young patients adopt more active coping strategies and have higher life satisfaction (Hamama-Raz et al., 2021).

The study also found that experiencing IBD helped youth mature and grow, reflected in their ability to cope with the disease positively and face challenges in life bravely. In other chronic disease studies (e.g., HIV, diabetes), such growth has been noted as post-traumatic growth (PTG), which remains understudied in patients with IBD (Hamama-Raz et al., 2021). A recent study revealed that illness cognition was an important component in facilitating the process of PTG among IBD patients. Given the importance of illness cognition in developing resilience, disease management and PTG, more cognition nursing measures should be taken to improve patient quality of life. Some studies have suggested that nurse-led cognitive/behavioural therapy could produce a favourable treatment outcome, including significant improvements in quality of life and other clinical outcomes (Tanoue et al., 2018; Yoshinaga et al., 2022).

A qualitative study on patients with UC found that positive coping strategies can stimulate mental resilience and ultimately affect patients' views on disease and life (Hassani et al., 2017). The current study found that some patients can adopt positive behavioural coping strategies. They can do especially well in self-management, which may promote resilience in young IBD patients. Self-management means enacting a series of behaviours with the goal of maintaining emotional and physical health in the setting of long-time chronic disease. Strong self-management skills and high-patient engagement can lead to healthy outcomes in IBD (Keefer & Kane, 2016). However, there were wide-ranging and complex challenges for the self-management of adolescent IBD patients (Malloy et al., 2022). Nurses should take a holistic approach to assessing the self-management challenges of adolescents with IBD and take appropriate nursing measures based on their specific needs.

Study findings revealed that life goals were factors that promoted resilience development in young patients with IBD. Some youth indicated that in order to realize the value of life and do what they love, they were determined and active in the process of treating IBD. To the best of our knowledge, previous studies of factors related to the resilience of adolescents with IBD have not focused attention on this aspect of resilience. However, research on the resilience of the elderly has demonstrated the importance of constructing survival motivation (Hassani et al., 2017). Suffering from IBD leads youth who are full of vision for the future to develop a deeper understanding of the value and significance of life. It is not difficult to understand why it is so important for young patients with IBD to realize the value of life. This finding suggests that nurses should focus on the dreams of young patients and help them set life goals.

Family support, peer support and other social support have often been described as factors that promote resilience (Kohut et al., 2021). However, our study found that these environmental factors may have two separate impacts on the resilience of young patients. These supports promote resilience in multiple ways. Care and economic support provided by the family meet patients' needs and give them confidence. Having a close and trusting relationship with clinical professionals offers patients psychological support and reduces anxiety. Moreover, patients who are peers can model

recovery and have a positive effect on adolescent patients. On the other hand, the incomprehension and prejudice of others (families, friends, classmates, teachers) make adolescent patients feel stigmatized, resulting in their unwillingness to communicate with others and in decisions to bear pressure alone. Therefore, nurses should recognize that environmental factors have two sides, and actively promoted positive environmental factors to develop resilience among adolescent patients with IBD.

For adolescent and young adult with IBD, the disease not only exacerbates academic pressure but also confuses them about the future. Young patients believe that IBD limits their personal development. They also worry that they may not be able to afford treatment expenses, either now as a family or independently in the future. Studies have also shown that patients who experience IBD symptoms for the first time when they are younger than 15 years old are less resilient in future career. This group also has lower acceptance of change than patients who are diagnosed with the disease at the age of 30 or older (Acciari et al., 2019). Nurses should pay more attention to young patients and carry out psychological nursing according to their needs (e.g., future life plan, career choice).

5.1 | Limitations

The study has some limitations. First, the sample was recruited from only one hospital in China. However, the hospital is a large national referral center in China and patients in the gastroenterology ward came from all over the country. Some influencing factors of resilience might be affected by cultural background and race. Further studies involving multiple regions and countries are needed to confirm and extend this study's results.

Second, as participants were interviewed only once, the promoting and hindering factors of resilience could not be observed directly over time. Findings were based only on patient memories, which may have influenced the credibility of this study.

Third, as with many qualitative studies, the sample size was small. A larger, more diverse sample may have elucidated more varied perspectives. Moreover, because of using qualitative method, the data that would quantify depression, pain or resilience was not collected. Future mixed-method research is needed, to show if youth with IBD who report more themes of hindering factors on resilience are indeed more depressed and/or less resilient, and to explore how best to provide support to these young patients and help them raise their levels of resilience.

6 | CONCLUSION

Based on Kumpfer's resilience framework, this study identified promoting and hindering factors of resilience among youth with IBD, dividing those factors into personal and environmental domains. The findings suggest that clinical professionals must develop greater awareness of factors, stemming from both the individual and the outside world, that hinder or promote resilience in order to aid young patients with IBD, and build targeted nursing measures. Some internal resilience factors described in the Kumpfer resilience framework were not included in our results, such as physical factors, so it is necessary to develop a resilience model for youth with IBD in future study.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version. Substantial contributions to conception and design: Lili You, Lingling Zhu, Yuxia Guan. Acquisition of data or analysis and interpretation of data: Lili You, Yangyang Wang, Tiantian Wang, Jing Dong. Drafting the article or revising it critically: Lili You, Siyao Wang, Xiang Yu.

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CONFLICT OF INTEREST STATEMENT

All authors have no financial or other relationships to report.

DATA AVAILABILITY STATEMENT

The data are available from the corresponding author.

ETHICS STATEMENT

The study was conformed to the Declaration of Helsinki and approved (July, 2020) by the Ethics Committee of the hospital from which participants were recruited and where interviews were conducted (No. S-K1682). Before commencing each interview, the interviewer explained the research aims and methods to each participant. Participants were informed that they had the right to withdraw from the study at any time. Written informed consent was obtained from all participants. For patients aged younger than 18 years, written consent was obtained from both the patient and the patient's parent(s).

ORCID

Siyao Wang https://orcid.org/0000-0003-1468-7918
Xiang Yu https://orcid.org/0000-0002-2762-8063
Yuxia Guan https://orcid.org/0000-0001-6490-0970

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