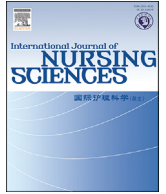


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## Original Article

## “I can fight it!”: A qualitative study of resilience in people with inflammatory bowel disease

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## ABSTRACT

**Objectives:** This study aimed to understand the resilience experiences in patients with inflammatory bowel disease (IBD) and develop the resilience framework for them.

**Methods:** Semistructured interviews were conducted with 15 patients with IBD who were purposefully recruited from the gastroenterology department of two hospitals in Jiangsu, China to gain diversity in the demographic and clinical characteristics. The data were analyzed using a directed content analysis approach based on the Kumpfer's resilience framework.

**Results:** The resilience framework for patients with IBD was formed from the analysis. This framework was composed of four themes, as follows: (1) complicated factors in the environment, (2) change the environment into a protective one, (3) personality traits, and (4) resilience-related coping.

**Conclusions:** The resilience framework for patients with IBD can effectively characterize the resilience experience of patients during the disease and assist healthcare professionals to understand how patients recover from the disease. More quantitative studies are needed to further explore the influencing factors of resilience and improve resilience in patient with inflammatory Bowel Disease.

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## 1. Introduction

Inflammatory bowel disease (IBD) includes Crohn's disease (CD) and ulcerative colitis, which affects approximately 0.5% people in Western countries [1]. With the changes in environment and diet, the incidence of IBD in East Asia has drastically increased. China ranks first in Asia, about 3.44/10 million people in China suffered from IBD [2]. Patients have to suffer from recurrent abdominal pain and diarrhea, as well as expensive treatment costs, which cause life restriction and the occurrence of negative emotions, such as anxiety and depression [3]. Although patients endured both physical and psychological distresses from IBD, some of these patients excel in dealing with distress and enjoy a high quality of life, who are considered to be resilient [4]. Resilience can relieve chronic patients' anxiety and depression [5]. Resilience is also positively correlated with self-efficacy and improved social support and quality of life in other diseases [6–8]. No uniform definition of

resilience has been observed since it may not be a single construct but complex processes influenced by both internal and external factors [9].

We speculated that resilience can make a sense in the course of IBD and improve patients' quality of life. However, empirical literature related to resilience in IBD is scarce. Melinder [10] claimed that adolescents who have low resilience have increased risk to develop IBD in adulthood. Small number of studies have investigated the concepts that belong to positive psychology, such as coping [11], self-efficacy [12], and equilibrium in IBD population [13]. However, these studies have not focused on resilience specifically, and none of these studies have explored the factors that can influence the resilience process.

The aim of our study is to understand why some patients with IBD suffer from both physical and psychological distresses while others still enjoy a high quality of life. Then, we develop a specific resilience framework for patients with IBD in this area of study.

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## 2. Methods

### 2.1. Design

The descriptive qualitative approach was used to explore the resilience experiences in patients with IBD. Semistructured, face-to-face interviews were performed. Individual interviews can avoid consensus effects and result in considerable data on personal experiences. All interviews were done by the same researcher. All interviews were completed in the conference room of the Department of Gastroenterology, First Affiliated Hospital of Nanjing Medical University and the Hospital of Nanjing Military Region. Only the researcher and participant were present at the time of the interview.

### 2.2. Recruitment

The maximum variation sampling approach was used to select participants purposely who are varied in age, gender, course of the disease, marital status, and working condition to gain diverse resilience experiences. Patients with IBD who were hospitalized from October 2016 to February 2017 in the Gastrointestinal Disease Center of the First Affiliated Hospital of Nanjing Medical University were considered to be recruited in our study if they met the following criteria: (1) diagnosed with IBD for at least 6 months, (2) conscious and can communicate in Chinese, and (3) provided written informed consent. Patients were excluded if they have other severe diseases, mental disorders, or verbal communication disorders, which may potentially compromise their responses to resilience experience. Potential participants were identified according to the recommendation of healthcare professionals in the gastrointestinal disease center or participants. The details of the study were explained to the targeted patients, and these patients were invited to participate. Recruitment stopped once participants from all a priori identified categories had been interviewed, and data analysis suggested the saturation of themes on the basis of the sample characteristics (i.e., no new code can be recognized in later interviews) [14]. The sample size in our study was 15 (Table 1).

### 2.3. Data collection

The predesigned interview guide was used to lead the interview. The interview guide was designed based on Kumpfer's resilience framework as well as literature review.

Kumpfer's resilience framework emphasizes that an individual

can interact with the environment actively or passively when faced with stressors or challenges and obtain a high quality of life through the dynamic process of resilience [15]. As a major life event, IBD may inevitably bring heavy stress and challenges to patients. Therefore, the experiences of resilience in IBD patients could be probed by Kumpfer's framework of resilience, which consists of six elements: stressor or challenge, the external environment context, person-environment interaction processes, internal resiliency factors, resiliency processes, and the positive outcome. The last part of the framework shows three possible outcomes caused by resiliency process: resilient reintegration, adaptation and maladaptation reintegration.

This study focused on the intrinsic factors and external environment of resilience, exploring the dynamic process of disease adaptation. Resilience results beyond the scope of our study. On the basis of the framework, we raised questions like "How did you recover from difficulties and challenges which the IBD brought to you?", "What helped or hindered you from recovering from IBD?" and "What qualities do you have to help you fight the disease?"

Meanwhile, we reviewed literature not limited to resilience, but we also included qualitative studies on IBD as reference. The guide begins with the question "What does IBD mean for you?" and other personal perceptions were solicited afterward, that is, "What are the difficulties and challenges that disease brings to your life?" In accordance to the semi-structured interview techniques, we permitted the order of questions to vary among participant on the basis of variations in individual narratives. When the patient's mood swings during the interview, we will terminate it. The interviews lasted for 30 min to 60 min. All interviews, expressions, tones, and actions of patients during the interview were recorded. The basic questionnaire (which included demographic information) was completed by participant before the interview.

### 2.4. Data analysis

The primary researcher listened to the recording repeatedly and transcribed it verbatim in Microsoft Word 2010 within 24 h. Transcripts were analyzed by two researchers by using directed content analysis method, which is recommended when existing theories or prior studies on a phenomenon are incomplete or will benefit from further description [16]. Two researchers scanned all transcripts to acquire a global recognition of the data in context. After highlighting the texts involving psychology resilience and giving a predetermined code from the Kumpfer's resilience framework [15],

**Table 1**  
Socio-demographic and clinical characters.

N	Sex	Age (years)	Marital status	Education level	Residence	Occupation	Type	Disease states	IBD Duration (years)
1	Male	73	Married	C	City	Retire	UC	Active	30
2	Male	23	Single	D	Country	Unemployed	CD	Remission	1
3	Female	29	Married	D	City	Full time	CD	Remission	0.5
4	Female	47	Married	B	Country	Unemployed	CD	Active	2
5	Male	30	Married	D	Country	Full time	CD	Remission	1
6	Female	86	Widowed	D	City	Retire	UC	Active	3
7	Male	30	Married	D	City	Full time	UC	Active	3
8	Female	54	Married	A	Country	Unemployed	UC	Active	4
9	Male	19	Single	D	City	Attend school	CD	Remission	0.5
10	Female	30	Married	D	City	Full time	CD	Remission	0.6
11	Male	43	Married	B	Country	Unemployed	UC	Active	3
12	Male	56	Married	C	Country	Retire	CD	Active	8
13	Male	20	Single	D	City	Attend school	CD	Remission	5
14	Female	20	Single	D	Country	Attend school	CD	Remission	5
15	Female	27	Single	D	City	Full time	CD	Remission	8

Note: A = Elementary school; B = Middle school; C = High school; D = College or higher; UC = Ulcerative colitis; CD = Crohn disease.

we compared the links among the codes. A new code will be given if the text cannot be categorized with the predetermined coding scheme. The research team met periodically to discuss about the emerged codes and reach a consensus on the concepts and themes.

### 2.5. Ethical considerations

All participants signed informed consent before the interview. Confidentiality was ensured by the principal researchers. Patients can withdraw from this study any time. The main researchers of this study are nationally certified psychologists that can cope up with the sudden situation during interviews. The study was approved by the First Affiliated Hospital with Nanjing Medical University Ethics Committee on Clinical Investigation.

### 2.6. Trustworthiness

Multiple methods were used to develop the trustworthiness of the findings guided by Lincoln and Guba [17]. The participants were selected with maximum variation sampling approach to acquire the variety of resilience experiences of patients with IBD, which enhanced the validity. To gain credibility, we used the template, and the first author interviewed all participants and analyzed the data [18]. Data and method triangulation guaranteed the credibility of the codes. We also presented relevant quotations to explain the categories further and strengthen the credibility [19]. To deal with credibility, we provided explanations on how to interpretation was performed for the readers to judge the analysis process [20] (Table 2). The research process was outlined step-by-step (including participant recruitment, data collection, analysis, and study circumstances) enhanced the transfer ability of the finding [21]. The description of the informants were used to portray the participants' feelings accurately.

## 3. Results

### 3.1. Participants

Participants were patients with IBD who were hospitalized from October 2016 to February 2017. The average age of participants was  $39.07 \pm 20.38$  years old.

### 3.2. Findings

Data were collected from people who living with IBD. The majority of the elements in Kumpfer's framework can be explained in this study, while some specific codes emerged from patients with IBD. Four major themes and 13 subthemes emerged from the data, as shown in Table 3. The resilience framework for patients with IBD was formed based on the main findings (Fig. 1).

#### 3.2.1. Theme 1: complicated factors in the environment

Five main external factors, which played dual roles in patient resilience process, were recognized, as follows: family, friends and peers, school and work, traditional culture, and technology development.

**Table 2**  
Example of the analysis.

Narrative Text	Concept	Subtheme	Theme
"When the doctor told me that I got the IBD, anyway, I felt heartbroken and unacceptable, but the family, especially my parents has been enlighten me and gave me a lot of help" [interviewee 5]	Emotional supports from family	Family protective factors	External environmental protective factors
"Whenever I feel bad, I will think of those who suffer from cancer or a car accident, compared with them I am very lucky and IBD is not so terrible" [interviewee 10]	Emotional coping	Cope with stress	Resiliency processes

**3.2.1.1. Subtheme 1: family.** Most of participants emphasized that family is the most important external support for them. Emotional supports, harmonious family atmosphere, understanding, and companionship were frequently mentioned by patients.

**3.2.1.2. Subtheme 2: friends and peers.** No discrimination and special care for diet from friends encouraged the patients. Some inappropriate ways of concern from friends was also detrimental to the patient's resilience.

A farmer with IBD shared his feeling, "She was too concerned about me and often told me some of the bad consequences of IBD, which makes me very upset." [Interviewee 11]

As a supplement to the Kumpfer's framework, people who also have IBD were seen as an influencing factor by our participants. The encouragements and disease management experience from peers were necessary strengths for patients. Meanwhile, the deterioration condition of others will make the patients feel sad and damage their self-efficiency.

**3.2.1.3. Subtheme 3: school and work.** Some patients emphasized the help they received from colleagues, while others expressed psychological distress when they were misunderstood by their teachers or employers. The different intensities of learning and work placed varied pressures and challenges on patients.

"Employers and colleagues are very concerned about me, supports from them gave me the confidence to overcome it (IBD)." [Interviewee 3]

"I am majoring in pharmacy, I worry that frequent leave will affect my studies." [Interviewee 13]

**3.2.1.4. Subtheme 4: traditional culture.** China has unique culture, such as share thick and thin and other dialectical thinking of adversity, which may promote patients to find the positive side of IBD and adapt to it well. Meanwhile, other traditional ideology, such as "Ren," may drive patients to repress their negative emotions.

An undergraduate boy with IBD said: "I seldom talk about my disease to my parents because I do not want them to worry about me." [Interviewee 13]

**3.2.1.5. Subtheme 5: technology development.** With the development of technology, patients learn disease knowledge through various ways, which provide promise in learning disease-related knowledge and increases their understanding of IBD. Meanwhile, technology shortens the distance between people and promote communication.

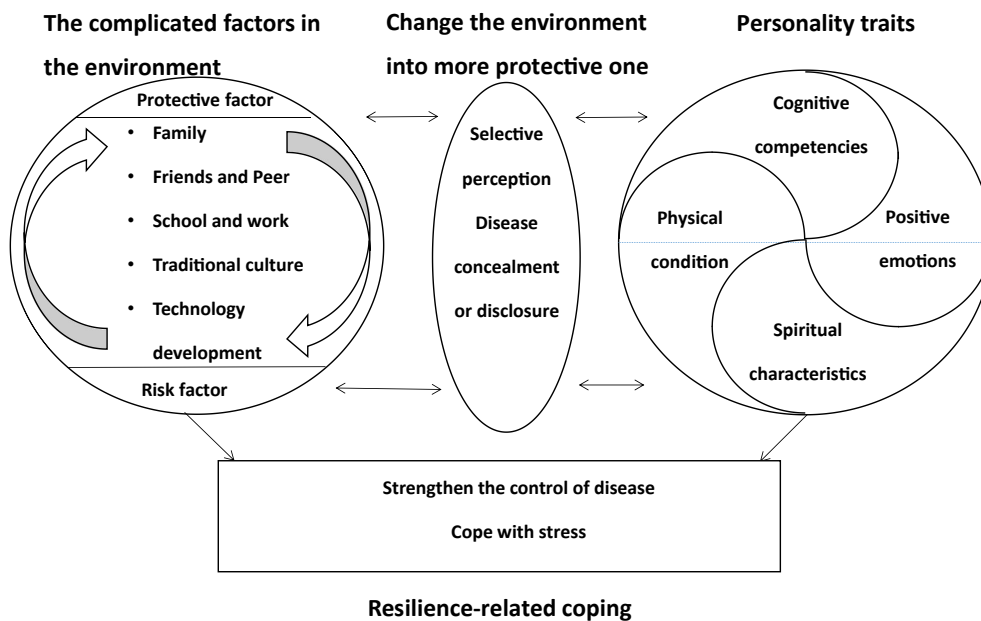
A grandma said, "WeChat helps me connect with my family and friends more frequently." [Interviewee 6]

#### 3.2.2. Theme 2: change the environment into a protective one

Participants tended to transform the environment around them. Two subthemes were described, as follows: selective perception and disease conceal or disclosure.

**Table 3**  
Themes and sub-themes that emerged from the qualitative coding.

Major Theme	Sub-themes
The complicated factors in the environment	Family Friends and Peer School and work Traditional culture Technology development
Change the environment into more protective one	Selective perception Disease concealment or disclosure
Personality traits	Cognitive competencies Positive emotions Physical condition Spiritual or motivation characteristics
Resilience-related coping	Strengthen the control of disease Cope with stress



**Fig. 1.** Resilience model for patients with inflammatory bowel disease.

**3.2.2.1. Subtheme 1: selective perception.** Participants tended to take advantages of protective environmental factors and avoid risky ones. For example, participants will selectively browse information online, ignoring negative information that may damage their mental health.

**3.2.2.2. Subtheme 2: disease concealment or disclosure.** Although some participants said disclosure of disease to others can help them adapt to the disease well, concealing this disease was also a common strategy that participants took to remain normal.

An old man with IBD for many years said, "People around me do not know what is IBD, they may think that the disease is infectious and consequently isolate me." [Interviewee 1]

**3.2.3. Theme 3: personality traits**

**3.2.3.1. Subtheme 1: cognitive competencies.** Studious, industrious, and curiosity were commonly seen in participants who adapted the disease well. When disease relapsed, some participants said that they will reflect and accumulate self-management knowledge from it.

"I am very curious like a child. Curiosity drives me to explore IBD which inspires me to conquer the IBD." [Interviewee 14]

**3.2.3.2. Subtheme 2: positive emotions.** Interviews showed that the participants that adapted to IBD well were those who are cheerful and optimistic. Humor was also an important quality that made patients laugh and propel them to find the positive aspects of the disease.

**3.2.3.3. Subtheme 3: physical condition.** Age appears to be a representative factor of physical condition. In our study, older people were easier to rebound from IBD than younger patients. Basic physical condition also should be taken into consideration.

As a young man said: "I am so young and need to take medicine for a lifetime, which make me feel desperate." [Interviewee 9]

A girl in our study said: "I was born in poor health, it is more difficult for me to rebound from IBD than the average person." [Interviewee 14]

**3.2.3.4. Subtheme 4: spiritual or motivation characteristics.** Spiritual characteristics, such as internal locus of control and self-efficacy, are necessary for resilient patients. Beliefs also play an important part. For Chinese who are edified by Confucian ethics, the impetus to fight IBD was the responsibility for the family.

One woman who was diagnosed with IBD when prepared to marry said, “Disease is under my control, we are a whole, I am good enough to improve the disease.” [Interviewee 3]

#### 3.2.4. Theme 4: resilience-related coping

Resilience-related coping is divided into two categories; one is disease-specific coping style, which is unique for IBD and the other one is common resilience coping style, which everyone would have when faced with life challenges.

**3.2.4.1. Subtheme 1: strengthening disease control.** Disease-specific coping style was used to strengthen the disease control by our participants, that is, obtaining knowledge on the disease through a variety of approaches and improving self-management ability energetically.

Arrangement and planning ahead were frequently used by some participants to lessen the inconvenience caused by disease.

A participant in college explained how he avoided the effect of the disease on his academics, “Under normal circumstances, I would plan in advance, adjusting the time to go to the hospital according to the schedule.” [Interviewee 13]

**3.2.4.2. Subtheme 2: cope with stress.** The stress coping strategy used by our participants can be divided into two categories, namely, behavioral and emotional coping methods. The behavioral coping methods, such as distracting attention by listening to music, shopping, sports, going out and travelling, or a resting (e.g., sleeping), were commonly used to relieve negative emotions and enhance strengths.

A soldier with IBD told us, “When I face the pressure, I will cry at will to release my negative emotions.” [Interviewee 7]

Social comparison is one of emotional coping method, which is often taken by participants to gain strength, that is, comparing themselves with those who are more unfortunate than them to gain comfort or learn from patients who have high treatment compliance. Some patients dealt with stress by losing temper or lashing out on others, which may cause damage both to themselves and others.

## 4. Discussion

Consistent with Kumpfer's resilience framework, environment can buffer or exacerbate the negative effects of stress on patients with IBD. Fergus and Zimmerman [22] suggested that although both protective and risk factors are mentioned in the framework, increased attention should be paid on protective factors. Previous practices in IBD emphasized the improvement of outcomes by recognizing and reducing barriers instead of finding and enhancing protective strength. Our participants emphasize the protective factors.

Similar to the results of Bernhofer [23], our findings showed that the majority of patients recognized family as the most important source of strength. Clinical nurses should evaluate the patient's family environment and encourage them to participate in patient disease management. Although friends were seen as a protective factor, misunderstanding of IBD from friends may harm the patient's resilience. Biased attitudes from others damage the patient's trust and affect their resilience [24]. The related knowledge of IBD in the crowds should be popularize. Peers were chosen as a supplement to Kumpfer's framework in our study. Goffman [25] pointed out that people who have the same “symbol” can form a sincere circle, from which one can obtain spiritual support and be truly accepted as normal people. Similar to the result of Arielle M. Silverman [26], our participants perceived others with IBD as a potential source of emotion or information support. However,

negative emotion or disease deterioration from peers may also damage the patient's resilience. Medical workers need to find effective ways to utilize peer resources.

Kumpfer's framework was designed specifically for teenagers; thus, school life is seen as a primary factor [16]. For adults, the influence of work cannot be neglected. The unpredictable, fluctuating nature of IBD makes many patients unemployed despite their desire and ability to work, thereby leading to anxiety and depression [27,28]. Many participants in our study recognized that understanding and support from employers and colleagues gave them strength to rebound from the disease, which was consistent with the results from the study of Teresa Lynch [29]. Meanwhile, another study [30] indicated that resilience and work has no relationship. On one hand, the government needs to consider launching a special employment policy for patients with IBD. On the other hand, as mentioned above, clinical nurses should popularize IBD knowledge not only to patients but also to their family members and friends to improve employers' and colleagues' awareness of the disease.

Regarding culture, China has a distinct culture different from those of Western countries. The religious belief in Kumpfer's framework was rarely mentioned by our participants. Confucianism such as “Ren” and “Li” in Chinese culture make Chinese people tend to repress their inner feelings and have strong endurance to psychology distress. Patients need be encouraged to share their feelings and take the initiative to seek outside help. Researchers paid attention to special traditional culture among different countries.

Technology advance is a new code, which was not included in Kumpfer's framework. The progress of science and technology expand the approaches for patients to obtain the disease information. Meanwhile, information explosion makes choosing the most useful knowledge difficult for patients, which may influence patient resilience. Cooper [4] found that patients with IBD are generally confused with information from different sources and want special IBD doctors or nurses. In addition to the advantages of telemedicine in improving patients' health-related quality of life [31], our participants highlighted the additional functions of technology in communicating with family and friends. Similar to the result of Khan S. [32], the use of telemedicine can promote communication and reduce isolation sense. According to Kumpfer's framework, the individual can adapt well under 1–2 risk factors, but the difficulty increases when more than two risk factors are present. Protective factors can also buffer the role of these risk factors, which suggested that health care providers should be attentive to the protective factors around the living environment of patients with IBD and assist them to eliminate the risk factors and improve their resilience.

Similar to Kumpfer's resilience framework, people with IBD were apt to transform the surrounding environment. Disease concealment or disclosure were frequently used. Some people concealed their disease due to the perceived taboo surrounding the symptoms of the disease [33], which was also reflected by our participants. Concealment may help patients create a false appearance of normal and avoid prejudice from others. However, it inevitably aggravates psychological burden and leads to the emergence of stigma [34]. Taking medication in certain occasions is difficult for patients because of disease concealment, thereby decreasing medication compliance. IBD disclosure is conducive to accept the disease, gain understanding, and receive support from other people [35]. Similar to the findings of Micallef [36], to study whether disclosure disease is context-dependent, our study emphasized on the importance of normalizing IBD and creating supportive environments for people with IBD.

Kumpfer proposed the opinion on the basis of literature review, showing that resilience is the dynamic process that people can

rebound from challenges. Resilient patients used a variety of methods to rebound from IBD. Our participants actively sought disease information [37]. The more knowledge the patients learned is, the easier it is to accept and manage IBD [38]. The Internet and health care workers are the main sources for this information. This result suggested that health care workers should pay attention to the patient's information needs and provide targeted information.

Some papers [39–41] showed that quality of life can be improved by a positive coping style. Behavior-focused strategies, such as distraction, were frequently taken by our participants to cope with stress [11]. Strategies such as social comparison and positive attitudes that is also called emotion-focused strategies are useful for patients to rebound from IBD, which was inconsistent with the conclusion from a meta-analysis [42], wherein emotion-focused strategies are negatively associated with health outcome. This disagreement may be due to the different strategies used. Distance and avoidance, which were mentioned by Penley JA [42], may harm the patients, while some emotion-focused strategies, such as social comparison, which have been used by our participants, may help patients with IBD to maintain normal life [43].

## 5. Limitations

Kumpfer's resilience framework has more elements than the one we used in this study. However, we also found some new elements, which were specifically present for patients with IBD. Some participants who have been diagnosed with IBD for a long time often provided their resilience experience through recalling. Reframing their memory to experiences may have influenced the credibility of this study. The participants in this study were only recruited from two hospital. Although both hospital are national first-class hospitals (third-grade class A) and patients in the gastrointestinal disease center all came from different parts of the country, the transferability of the results will be affected. Other multicenter studies that use longitudinal design are needed to explore the process of resilience and verify the accuracy of the resilience framework for patients with IBD.

## 6. Conclusion

The resilience framework for patients with IBD can effectively characterize the resilience experience of patients during the course of the disease and assist healthcare professionals to understand how patients recover from disease. However, differences in resilience factors and process are significant among individuals, and other multicenter longitudinal studies are needed to verify the accuracy of this framework.

## Conflicts of interest

The authors have no financial support or conflicts of interest to report.

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