

The Mediating and Moderating Role of Resilience Between Stigma and Illness Identity Among People with Inflammatory Bowel Disease

Lichen Tang¹, Zheng Lin^{1,2}

¹School of Nursing, Nanjing Medical University, Nanjing, 211166, People's Republic of China; ²Nursing Department, the First Affiliated Hospital with Nanjing Medical University, Nanjing, 210029, People's Republic of China

Correspondence: Zheng Lin, School of Nursing, Nanjing Medical University, Tianyuan East Road No.818, Jiangning District, Nanjing, Jiangsu, Email linzheng100@163.com

Background: Stigma is assumed to lead to negative illness identity in one who got chronic illness, and there is a lack of understanding regarding the underlying mechanisms. However, no research has examined the extent to which stigma was associated with illness identity in people with IBD. Therefore, we investigated the relationship between stigma and illness identity, specifically to examine whether resilience mediated or moderated the relationship.

Methods: A cross-sectional study was performed among patients diagnosed with inflammatory bowel disease from three tertiary hospitals in Jiangsu Province, China. Measurement instruments included the Stigma Scale for Chronic Illness (SSCI), the Resilience Scale for Patients with Inflammatory Bowel Disease (RS-IBD), and the Illness Identity questionnaire (IIQ). Mediation and moderated mediation analyses were conducted.

Results: A total of 322 patients with IBD were involved in the current study. We observed that there was a strong connection between stigma and rejection and engulfment. Moreover, resilience played a partial or complete mediating role in stigma and engulfment, acceptance and enrichment, and resilience moderates the relationship between stigma and rejection.

Conclusion: The current study examined whether resilience mediated or moderated the relationship between stigma and illness identity. These findings add to the theoretical basis of how stigma influences illness identity and help guide the resilience into engulfment reduction programs for IBD.

Keywords: inflammatory bowel disease, stigma, illness identity, resilience

Introduction

Inflammatory bowel disease (IBD), mainly including ulcerative (UC) and Crohn's disease (CD), is a chronic, recurrent, and immune-mediated gastrointestinal disease.¹ Patients with IBD suffer from abdominal pain, persistent diarrhea, mucopurulent bloody stool, weight loss, and fatigue throughout their lifetime repeatedly.^{2,3} At present, IBD is incurable, and the disease duration can reach several years or even decades, with alternating periods of relapse and remission, and the overall trend is gradually aggravated.⁴ Available treatments typically consist of specific dietary restrictions (eg, Exclusive Enteral Nutrition, the Low FODMAP Diet, and the Specific Carbohydrate Diet), plus taking medication such as corticosteroids and biologicals, but the above methods have no response to some patients, or the efficacy is weakened by the use of time.^{5,6} Therefore, in severe cases, abdominal stoma and intestinal resection may be needed to maintain stable condition.⁷ The suffering caused by disease progression, the adverse side effects associated with clinical treatment (eg, impaired body image and impaired fertility), and the high cost of medical care impose a heavy physical and mental burden on patients.^{8,9}

Compared with healthy people, IBD patients have a higher risk of psychological problems, patients are accompanied by different degrees of emotional disorders regardless of whether they are in the stage of symptom recurrence or remission.¹⁰ A series of recent studies on the life experience of IBD have found that patients face many challenges

adapting to the disease, including unpredictable bowel symptoms that disrupt patients' goals, social and daily functioning, require them to change their priorities and adjust their future plans, and lead to a variety of adverse psychosocial problems, such as emotional turmoil, low levels of self-worth, a sense of identity loss, and often the need for patients to "striving towards normality" by finding an equilibrium between their lives before and after diagnosis.^{11–14}

As the new illness identity (after experiencing the torment of disease symptoms and painful life experience) conflicts with the current self-concept, the patient needs to find a way to integrate their IBD into their own identity to accommodate the illness, a process captured by the concept of illness identity.^{15,16} Oris and colleagues developed four types of illness identity,^{17,18} and two positive illness identities included (1) acceptance is the degree to which illness is accepted as part of personal identity; and (2) enrichment refers to illness that enriches and grows an individual's sense of self. The two negative disorders are identified as (1) engulfment whereby the illness completely dominating identity; and (2) rejection means that the illness is perceived by the individual as a threat and unacceptable to the self. In fact, depending on the actual situation, rejection also could be divided into adaptive (preventing overwhelming events and feelings) and maladaptive (pathological, ineffective defense mechanisms).¹⁹

Recent studies have confirmed that illness identity a key indicator to measure the individual's disease adaptation status, and plays an important role in the mental health assessment of IBD.²⁰ It has been shown that relatively high levels of engulfment in patients with IBD are associated with higher depressive symptoms, lower life satisfaction, poorer health, and reduced quality of life.²¹ However, positive identity adjustment is associated with successful adaptation to the disease, which has far-reaching implications for improving patient health-related outcomes.²² Therefore, it is critical to identify the variables that influence the identity of patients with IBD and to explore measures to improve their disease adaptation.

Recently, Yanos and colleagues proposed an illness identity model based on recovery from severe mental illness that suggests that stigma is considered a prominent psychosocial variable that impairs illness identity.²³ Unpleasant odors, the risk of incontinence in public, the need for an ostomy, and burdens to others make IBD patients experience stigma.²⁴ Stigmatization in IBD patients was reported to be as high as 84%, regardless of disease activity.²⁵ O'Donnell et al found that stigma was positively correlated with illness self-concept(similar to engulfment-like state) and significantly negatively correlated with enrichment.²⁶ Literature outside the field of IBD suggests that higher stigma leads to a negative illness identity, while deepening hopelessness and low self-esteem, leading to a decrease in social engagement and an increased risk of suicide, thus creating a vicious cycle.²⁷ However, the specific mechanisms by which stigma affects illness identity in patients with IBD remain unelucidated.

Resilience can be another important aspect of illness identity. Resilience is the ability to find resources to act, manage, adapt, and recover in the face of and after adverse situations.²⁸ Resilient patients are able to overcome disease-related crises through personal, social, and environmental interactions, which facilitates positive identity adjustment.²⁹ Existing research has confirmed that perceived stigma impairs an individual's resilience, which in turn leads to a poorer quality of life for people with IBD.³⁰ Furthermore, resilience is considered a protective factor in maintaining the mental health of IBD patients, and higher levels of resilience are associated with higher levels of psychosocial adjustment.³¹ Specifically, individuals with high resilience have stronger self-control ability and better psychological adjustment, which can better ensure the close integration of illness and personal self-awareness. Similarly, Martínez and colleagues reported that resilience can positively predict the formation and development of an individual's self-concept.³² The above evidence suggests that stigma may impair resilience, and in turn affects illness identity. However, to our knowledge, no studies have analyzed the relationship between stigma, resilience and illness identity in people with IBD.

In this study, we assessed the role of resilience as a mediator, which may explain the relationship between stigma and illness identity in IBD patients. Based on the above information, we hypothesize that (H1) stigma is associated with illness identity in IBD patients, and (H2) resilience will mediate or moderate the relationship between stigma and illness identity in IBD patients.

Materials and Methods

Patients and Procedure

Convenience sampling was used to enroll participants who with 322 IBD from three tertiary hospital in Nanjing, Jiangsu Province, China, between March and September 2023. The selection of IBD patients was based on the following criteria:

(a) diagnosed with UC or CD; (b) age \geq 18 years; (c) disease duration of more than 6 months; (d) able to comprehend and answer the survey questionnaires. Exclusion criteria included: (a) patients with malignant tumors or other anorectal diseases; (b) patients with known severe mental illness or cognitive impairment. Investigator met with all patients who responded to the study and referred by their charge nurse, confirmed the study criteria, and introduced the purpose, procedures, and potential benefits and risks of the study. All the patients were asked to give written informed consent if they were eligible for the study. All the patients were asked to give written informed consent before completing the questionnaire.

Measurements

Patients complete a set of self-reported questionnaires that require demographic characteristics to assess the age, gender, education level, marital status, work status, residence, and family income. Clinical information such as disease type, duration, disease activity, use of biologics, presence or absence of a stoma, nasogastric feeding.

Stigma

We used a validated Chinese version of the Stigma Scale for Chronic Illness (SSCI) for chronic disease to assess the stigma of people with IBD.³³ The scale contains 24 items, comprising two dimensions: intrinsic stigma (13 items) and extrinsic stigma (11 items). A five-point Likert level score (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = almost always) is used, with the total score between 24 and 120 points. The higher the score, the stronger the level of stigma. The Chinese version of SSCI has sufficient reliability in IBD patients (The Cronbach's α was 0.965).³⁴

Resilience

Resilience was measured by the Resilience Scale for Inflammatory Bowel Disease (RS-IBD) is a specific resilience tool developed by Dan L et al for patients with IBD in China.³⁵ The 25-items RS-IBD scale showed excellent validity and validity, divided into six dimensions: disease management, active coping with difficulties, positive cognition, emotional regulation, family support and patient support. Using the Likert 5-level scoring method, from "never" to "always" is calculated 1~5 points, the total score ranges from 25 to 125, the higher the score indicates the higher the patient's mental resilience level.

Illness Identity

The Illness Identity questionnaire (IIQ), designed by Oris et al,¹⁷ and later translated and cultural adaptation to form a Chinese version by the author's research group, was adopted to evaluate the level of chronic illness identity. The Chinese version includes 24 items and involves four dimensions, rejection (5 items), acceptance (4 items), engulfment (8 items), and enrichment (7 items). Responses to each item are graded from "totally disagree" to "absolutely agree" on a scale of 1 to 5. This scale was reliable and valid in Chinese-speaking populations with IBD which been verified by our previous study. The Cronbach's α of four dimensions respectively were 0.780, 0.800, 0.921, 0.917, and the acceptable model fit indexes were found: $\chi^2/df = 1.831$, $GFI = 0.865$, $IFI = 0.938$, $CFI = 0.938$, $RMSEA = 0.060$.

Statistical Analysis

IBM SPSS 26.0 was used to perform all statistical analysis. Prior to analysis, the normality of variables was assessed by examining skewness and kurtosis values. We conducted descriptive statistics to describe the characteristics and distribution of IBD. We studied the relationships among stigma, resilience and illness identity using Pearson correlation. Hierarchical multiple regression models were employed to investigate whether resilience mediated or moderated the relationship between stigma and illness identity. Additionally, a bias-corrected bootstrapping analysis (with 5000 resamples) via the PROCESS macro program was adopted to test the indirect and moderating effect of resilience on the pathway between stigma and illness identity. If the absence of a zero in the confidence intervals, the statistical significance was indicated. Finally, a simple slope analysis was conducted to analyze the moderating effect of resilience further. The significance level set at 0.05 for all the analyses.

Ethical Considerations

The study complied with the Declaration of Helsinki and was approved by the Ethics Committee of Nanjing Medical University (No. (2022) 795). All the participants signed informed consent.

Results

General and Illness-Related Characteristics of Participants

Table 1 summarizes the sociodemographic and clinical characteristics of 322 Chinese participants with IBD. The mean age of participants was 35.71±12.44 years (mean ± standard deviation), and 68% were male. More than half of the participants (58.4%)

Table 1 General Characteristics of the Participants (N=322)

Characteristic	Classification	N(%)
Gender	Male	219 (68.0)
	Female	103 (32.0)
Age (year)	18~25	74 (23.0)
	26~45	178 (55.3)
	≥ 46	70 (21.7)
Education level	Primary education	88 (27.3)
	Secondary education	46 (14.3)
	Higher education	188 (58.4)
Marital status	Unmarried	118 (36.6)
	Married	194 (60.2)
	Divorced/Widowed	10 (3.1)
Residence	City/Town	250 (77.6)
	Country	72 (22.4)
Family yearly income (yuan)	<50, 000	115 (35.7)
	50, 000~100, 000	84 (26.1)
	>100, 000	123 (38.2)
Disease type	Crohn	234 (72.7)
	Ulcerative colitis	88 (27.3)
Disease duration (year)	<1	100 (31.1)
	1~5	136 (42.2)
	>5	86 (26.7)
Disease activity	Remission	237 (73.6)
	Active stage	85 (26.4)
Biological Agents	Yes	209 (64.9)
	No	113 (35.1)
Abdominal wall stoma	Yes	9 (2.8)
	No	313 (97.2)
Nasal feeding	Yes	24 (7.5)
	No	298 (92.5)

had higher education, and 60.2% were married. In terms of residence, 77.6% of participants lived in urban areas, while only 38.2% had family income of 100,000 yuan or more. About disease type, 72.7% of patients were diagnosed with Crohn's disease. Regarding disease duration, 26.7% of participants were diagnosed with IBD for more than five years, with the majority (73.6%) in remission. In addition, 64.9% of patients were treated with biologics to control their condition, and a minority of patients were undergoing nasal feeding (7.5%) and abdominal wall stoma (2.8%).

Correlations Among Stigma, Resilience, and Illness Identity

Table 2 shows the mean, standard deviation (SD) and Pearson correlation for the four dimensions of stigma, resilience, and illness identity. Pearson correlation analysis showed that stigma was negatively correlated with resilience ($r=-0.483$, $p<0.01$), acceptance ($r=-0.217$, $p<0.01$) and enrichment ($r=-0.205$, $p<0.01$), but positively correlated with rejection ($r=0.380$, $p<0.01$) and engulfment ($r=0.707$, $p<0.01$). Resilience is positively correlated with acceptance ($r=0.307$, $p<0.01$) and enrichment ($r=0.530$, $p<0.01$), but negatively correlated with rejection ($r=-0.266$, $p<0.01$) and engulfment ($r=-0.428$, $p<0.01$).

Testing for Mediation Model

Whether resilience mediates the relationship between stigma and illness identity in patients with IBD was tested using hierarchical regression (Table 3). The original model included both direct and indirect effects, and stigma have nonsignificant direct effect on acceptance ($b=-0.015$, $p=0.137$) and enrichment ($b=-0.022$, $p=0.220$). Therefore, the pathways are limited to zero. In addition, the mediating effect of resilience between stigma and rejection ($b=-0.030$, $p=0.067$) is ineffective. Resilience plays a partial mediating role between stigma and engulfment ($b=-0.056$, $p=0.012$). Figure 1 show the mediation model of engulfment, acceptance and enrichment. Subsequently, we used the SPSS 26.0 PROCESS macro procedure to verify the mediating role of resilience between stigma and illness identity (acceptance, enrichment, engulfment) (Table 4). The bias-corrected percentile bootstrap results showed that resilience completely mediated the association between stigma and acceptance ($B=-0.056$, 95% BCa CI[-0.089, -0.026]) and enrichment ($B=-0.149$, 95% BCa CI[-0.202, -0.104]), and had a partial indirect effect on engulfment, with an estimated value of 0.035. The 95% confidence interval (CI) for indirect effects was [0.006, 0.069].

Testing for Moderation Model

Whether resilience buffers the effect of stigma on illness identity was tested using stratified regression. Based on the previous step, a significant bidirectional interaction (stigma * resilience) was observed only in the predicting rejection ($b=0.002$, $p=0.035$), indicating that resilience has a moderating effect in the pathway of stigma to rejection. The SPSS 26.0 PROCESS macro analysis yielded bias-corrected percentile bootstrap results (Table 5), with a moderated mediation index of 0.002. The 95% confidence interval (CI) was [0.001, 0.003]. To further understand the moderating effect of resilience, a simple slope analysis was performed by taking the mean of resilience plus 1 standard deviation and the score of its mean minus 1 standard deviation. The results showed that stigma had a significant effect on rejection when resilience was high ($b_{simple} = 0.121$, $p<0.001$). Stigma also predicted rejection when resilience was low ($b_{simple} = 0.071$,

Table 2 Correlations Between Study Variables

Variable	Range	Mean (SD)	1	2	3	4	5	6
1. Rejection	5~25	14.01 (4.28)						
2. Acceptance	4~20	15.13 (2.69)	-0.206**					
3. Engulfment	8~40	20.53 (7.61)	0.373**	-0.212**				
4. Enrichment	7~35	26.19 (5.33)	-0.180**	0.415**	-0.203**			
5. Stigma	24~120	42.71 (16.17)	0.380**	-0.217**	0.707**	-0.205**		
6. Resilience	25~125	97.87 (15.53)	-0.266**	0.307**	-0.428**	0.530**	-0.483**	

Note: ** $p<0.01$.

Table 3 Hierarchical Regression Examining the Effect of Resilience on the Relationship Between Stigma and Illness Identity (N=322)

Variable		M (resilience)					Y (rejection)				Y (acceptance)				Y (engulfment)				Y (enrichment)						
		b	SE	95% CI	p		b	SE	95% CI	p	b	SE	95% CI	p	b	SE	95% CI	p	b	SE	95% CI	p			
X (stigma)	a	-0.464	-0.047	(-0.556, -0.371)	<0.001	c'	0.087	0.016	(0.056, 0.117)	<0.001	-0.015	0.010	(-0.035, 0.005)	0.137	0.307	0.021	(0.265, 0.348)	<0.001	-0.022	0.018	(-0.013, 0.057)	0.220			
M (resilience)						b	-0.030	0.016	(-0.062, 0.002)	0.067	0.046	0.011	(0.025, 0.066)	<0.001	-0.056	0.022	(-0.099, -0.012)	0.012	0.193	0.019	(0.156, 0.229)	<0.001			
		R ² =0.233 ΔR ² =0.233 F _(1,320) =97.286 p<0.001					R ² =0.153 ΔR ² =0.009 F _(2,319) =28.836 p<0.001					R ² =0.100 ΔR ² =0.053 F _(2,319) =17.765 p<0.001					R ² =0.509 ΔR ² =0.010 F _(2,319) =165.492 p<0.001					R ² =0.284 ΔR ² =0.242 F _(2,319) =63.317 p<0.001			

Note: unstandardized beta coefficients were reported.

Abbreviation: SE, standard error.

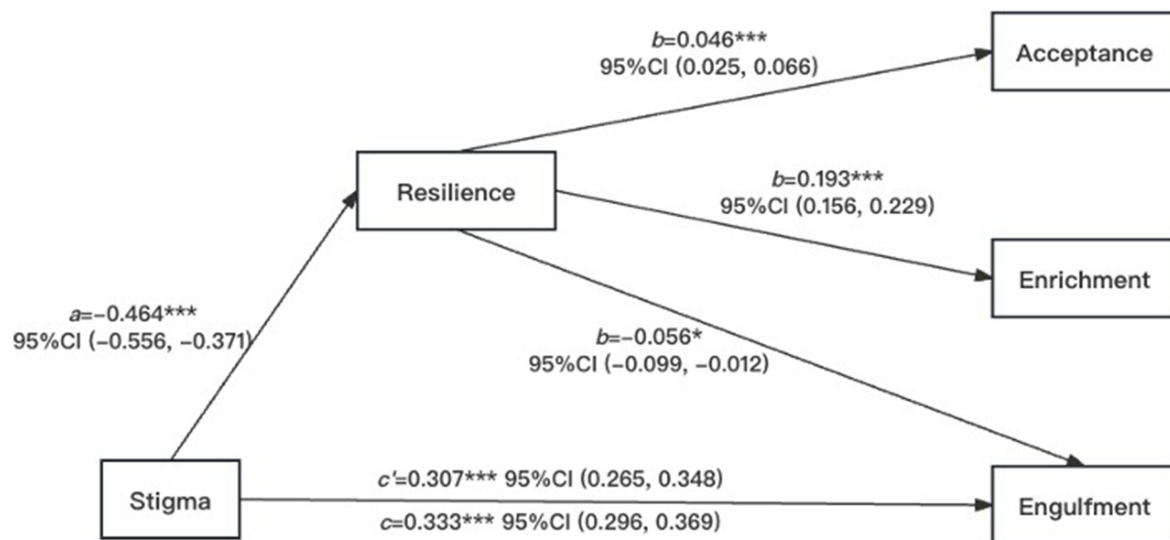


Figure 1 The mediation model of stigma, resilience, illness identity (acceptance, enrichment, engulfment). a The effect of stigma on resilience; b The effect of resilience on illness identity; c The total effect of stigma on illness identity; c' The direct effect of stigma on illness identity; *** $p < 0.001$, * $p < 0.05$. Unstandardized beta coefficients were reported.

$p < 0.001$). As shown in Figure 2, the positive predictive relationship between stigma and rejection is enhanced when resilience is high (eg, one standard deviation above the mean).

Discussion

The current study is the first to shed light on how stigma affects illness identity in people with IBD. As expected, The main findings of this study are: (1) there is a strong connection between stigma and rejection and engulfment, (2) resilience plays a partial or complete mediating role in stigma and engulfment, acceptance and enrichment, and (3) resilience moderates the relationship between stigma and rejection.

The results of this study are consistent with previous studies, and support a positive correlation between stigma and rejection and engulfment.^{26,36} Intestinal symptoms are often seen as a shameful experience of “uncleanness”, and can

Table 4 The Bootstrap Results of Mediation Analysis

	Effects	Engulfment			Acceptance			Enrichment		
		Coeff.	SE	95% CI	Coeff.	SE	95% CI	Coeff.	SE	95% CI
Stigma	Total effect	0.504	0.029	(0.448, 0.560)	-0.111	0.028	(-0.165, -0.056)	-0.117	0.031	(-0.179, -0.055)
	Direct effect	0.469	0.032	(0.407, 0.531)	-0.055	0.030	(-0.114, 0.004)	-0.032	0.030	(-0.027, 0.090)
	Indirect effect through resilience	0.035	0.016	(0.006, 0.069)	-0.056	0.016	(-0.089, -0.026)	-0.149	0.025	(-0.202, -0.104)

Abbreviations: Coeff, coefficient; SE, standard error.

Table 5 The Bootstrap Results of Moderating Effect

	Coeff.	SE	95% CI
Stigma → Resilience → Rejection Index of moderating effect	0.002	0.001	(0.001, 0.003)
Low resilience	0.071	0.017	(0.037, 0.105)
High resilience	0.121	0.023	(0.077, 0.165)

Abbreviations: Coeff, coefficient; SE, standard error.

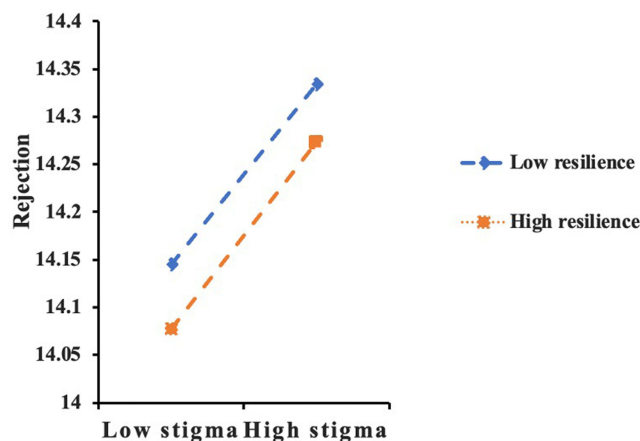


Figure 2 Moderating effect of resilience on the pathway from stigma to rejection.

weaken a person's self-identity.³⁷ The insight paradox^{23,38} also points out that the negative appraisals related to the disease are highly amplified by clinical insight, especially obvious when stigma is combined with negative identification with the disease, leading patients to believe that their disease is serious and incurable. This is followed by avoidant coping, low service engagement and social isolation, which ultimately leads to aggravation of the disease.

The most notable finding was that resilience was partially mediated the relationship between stigma and engulfment. This suggests that boosting resilience may weaken their engulfment, that is, a state in which the “patient” role taking on a primary identity. According to McCay et al, poor self-efficacy and low self-esteem was correlated with higher levels of engulfment.³⁹ Although resilience as a mediation between stigma and engulfment has never been reported, it is reasonable given that resilience is characterized by the promotion of self-esteem, self-confidence, and personal rebuilding.²⁹ Furthermore, our outcome shows that resilience mediates a significant but relatively weak link between stigma and engulfment. This may be because individuals' identity is in engulfment situation, specifically, when illness is seen as a burden and affects many other areas of the living space,⁴⁰ whereas resilient isolated actions may be more conditional, and more likely to be combined with other protective variables (eg, optimism, goals, social support) to respond more effectively.^{41,42} So far, small steps have been taken to introduce a positive psychology framework in the area of improving engulfment programs. For example, Konsztowicz et al⁴³ developed an intervention program based on cognitive behavioral therapy, drawing on positive psychology and narrative therapy. After 4–6 weeks of intervention, results indicated that patients had an obvious reduced sense of engulfment, increased self-esteem, and more active participation in treatment and rehabilitation. However, it remains to be explored whether this engulfment change could be effectively translated into a more adaptive recovery mode and continue play a role.

Although this study has not found a direct relationship between stigma and acceptance and enrichment, the stigma of IBD patients indirectly affected acceptance and enrichment through resilience. As an important psychological resource, resilience had a positive effect on acceptance and enrichment. Recent studies have shown that resilience is dynamic and can be trained, especially in people with isolation and stigma.⁴⁴ In addition, neurological evidence revealed that resilience can counteract catecholamine and cortisol responses and invoke specific brain structures and neural circuits that help individuals regulate their emotions and adopt adaptive social behaviors.⁴⁵ Therefore, resilience could be considered an effective protective strategy to optimize the negative emotions of patients. In the difficult survival experience of IBD, the need for interventions to improve resilience, help patients recover from adversity and actively adapt to adversity is highlighted.

In this study, despite we found that the mediating effect of resilience between stigma and rejection was not significant, resilience can moderate the association between stigma and rejection. Surprisingly, the results obtained so far do not agree with our assumptions. Specifically, in patients with low resilience, experiencing stigma increases the likelihood of rejecting identity. However, for resilient patients, this relationship is weakly enhanced, which we suggest may trigger the positive attributes of rejection. In the current study, when the positive dominance of resilience conflicts with the “persistent” nature of high stigma, patients tended to opt for rejection defense mechanisms, trying to limit negative

emotions and reduce illness stress by inhibiting, denying, or distracting. This view is supported by the findings of Peters et al,²² which is now considered to be an important part of the psychobehavioral strategies in the adaptation process of IBD patients, which can be used to enhance the coping capacity of patients to cope with complex physical and mental health conditions. Similar results have been found in patients with kidney disease and cancer, who believe that the defense mechanism of denial helps to protect themselves.^{19,46} Nonetheless, these possibilities should be assessed with caution. We previously emphasized that rejection is a maladaptive condition, which seems to be valid under a single condition.²¹ However, the agency and internal control advantage of high resilience in this study cannot be ignored,²⁹ so high resilience may elicit an adaptive mechanism of rejection in the face of the overwhelming suffering of high stigma, but the exact mechanism of this possibility needs to be further studied. In addition, most of the patients included in this study had a longstanding history and a low disease activity, which could represent a bias in interpreting the results.

Limitations

Caution is needed in interpreting the current findings, as our study has some limitations. First, the cross-sectional design used in this study makes it challenging to establish causal relationships between variables. In addition, “illness identity” is still a latent variable of unstable nature. It is a possible that the level may change with the environment and disease condition, further longitudinal studies are therefore needed. Second, by focusing solely on the effect of resilience on stigma and illness identity in IBD patients, this study could not explain other factors. Such as potential psychosocial mediating variables (such as self-esteem, mastery, and optimism) are important components of resilience and have not been analyzed. In addition, the results of this study should be generalized with caution as the sample of this study was primarily based on non-randomized participation, and the study relied on self-reported questionnaires, which may be biased due to differences in symptoms, individual differences (e.g., reading comprehension ability).

Conclusion

In conclusion, we found the evidence in this study to support the mediating role of resilience between stigma and engulfment, acceptance, and enrichment, and the moderating effect of resilience on the relationship between stigma and rejection. Therefore, it would be advisable that principles of promoting resilience be incorporated into interventions for illness identity integration, and that positive psychological resources that can combat stigma and adjust illness identity need to be further identified and expanded in the future.

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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