RESEARCH ARTICLE

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The actuality of resilience, social support and quality of life among patients with inflammatory bowel disease in China

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Abstract

Aim: This study was conducted to increase knowledge on the actuality of resilience, social support and quality of life among inflammatory bowel disease patients in China to provide evidence for psychological support.

Design: Using convenience sampling, 249 outpatients and inpatients with inflammatory bowel disease from a hospital who completed the questionnaires were enrolled in the analytic questionnaire-based study.

Methods: Demographic information forms, Resilience Scale for Inflammatory Bowel Disease, Social Support Rating Scale and Short Health Scale were administered.

Results: It was found that the resilience of patients with inflammatory bowel disease should be enhanced. When considering factors that influence resilience, the place of residence (living in rural areas) and utilization of social support should be considered. Resilience demonstrated a positive correlation with utilization of social support, and different place of residence was related to resilience. Targeted interventions should be implemented to increase patients' resilience and quality of life.

KEYWORDS
actuality, Inflammatory bowel disease, quality of life, resilience, social support

1 | INTRODUCTION

Inflammatory bowel disease (IBD) is one of the most common chronic disorders, and it mainly includes ulcerative colitis (UC) and Crohn's disease (CD) (Rubin et al., 2012). The incidence of IBD in China, 3.44 cases per one million (total population 1.4 billion), is the highest in Asia (Farrell & Savage, 2012). As of 2017, IBD affects 6.8 million people worldwide. The highest incidence proportion for IBD was reported in the United States (464.5 cases per 100,000 population) followed by UK (449.6 cases per 100,000 population) (Alatab et al., 2020). Epidemiological studies have indicated that the incidence rate of IBD in the Chinese mainland is higher in the south and lower in the north. IBD is characterized by non-infectious chronic inflammation of the gastrointestinal tract which commonly present with abdominal pain, diarrhoea, rectal bleeding, weight loss and perianal disease. The chronic and recurrent illnesses are reported to lead to a negative impact on physical and mental states and social competence of patients affected (Mikocka-Walus et al., 2016), which aggravates the condition or increases its recurrence (Neuendorf et al., 2016), ultimately resulting in a vicious circle.

Resilience is the ability to successfully recover from traumatic, stressful and painful events and to adapt to one's new life (Southwick et al., 2014). As a vital factor in protecting psychological health, resilience has been recognized as the capacity to "bounce back" (Harrison, 2013) following events and setbacks in life. Several previous studies have revealed that resilience was conducive in producing positive emotions, making self-adjustment and

maintaining a positive attitude to the disease for patients affected (Gao et al., 2019; Tzuriel & Shomron, 2018). Social support, defined as emotional or behavioural support provided by families, friends or other groups, was revealed as an influential factor on resilience in a previous study (Mealer et al., 2012).

To date, the psychological management strategies of IBD in China have not yet fully matured, and attention to the psychological problems of patients with IBD and related social problems remains insufficient. Previous studies on resilience might not well reflect the actuality of resilience among patients, as an international universal scale was often employed in those studies, which did not consider the specificity of patients with IBD (Fenwick-Smith et al., 2018). The present study aimed to investigate the current state of resilience of IBD patients and analyse the relationships of resilience, social support, quality of life which would provide a theoretical reference for clinicians to develop practical measures.

1.1 | Research question

The research question was as follows: What is the actuality of resilience of patients with IBD in China? What is the relationship between resilience and social support, quality of life among patients with IBD by using the Resilience Scale for Inflammatory Bowel Disease (RS-IBD), the Social Support Rating Scale (SSRS) and the Short Health Scale (SHS). Therefore, such results can provide evidence for medical workers to ameliorate patients' psychological state and boost their mental and life quality.

2 | METHODS

2.1 | Design and sample size

A convenience sample of 249 inpatients and outpatients with IBD from a hospital in Hunan province, China, was enrolled in this study from September–December 2019. The researchers contacted the head nurse of the gastroenterology department of the hospital, who introduced the purpose and content of the study to IBD patients and sent them questionnaires through Wen Juan Xing (www.wjx.cn, a Chinese survey website). The patient inclusion criteria were as follows: confirmed diagnosis of IBD, having received education at least in primary school and having literacy and cognitive abilities, aged 18 years or older and willingness to participate in the study. The exclusion criteria were as follows: diagnosis of other intestinal and anorectal disorders, diagnosis of cancer, heart and cerebral vessels disease and any condition that impairs psychological state and diagnosis of mental disorders such as bipolar disorder, depression, anxiety disorders and schizophrenia. In this study, a total of 254 questionnaires were distributed, of which 249 were valid, with five invalid or incomplete questionnaires being eliminated.

2.2 | Measurement of variables

2.2.1 | Demographic information

Information on gender, age, disease type, medical fee, payment methods, education, marital status, place of residence, annual income of family, previous surgery, smoking status, alcohol status and previous hospitalization frequency for IBD were all collected.

2.2.2 | Resilience scale for inflammatory bowel disease

Resilience Scale for Inflammatory Bowel Disease (RS-IBD) is a resilience scale for the IBD patients in China developed by Dan Luo (Luo et al., 2018). It is divided into six dimensions, including self-management on disease (four items), active response to difficulty (six items), positive cognition (five items), emotional regulation (four items), family support (three items) and other patients' support (three items), with a total of 25 items. Cronbach's alpha coefficient of the scale is 0.941 and that of each dimension ranges between 0.743–0.833. Furthermore, Cronbach's alpha of RS-IBD in the present study was 0.931. It uses a five-point Likert scale, and the higher the score, the higher the level of resilience. The total score is the sum of the 25 items (range is 0–100).

2.2.3 | Social support rating scale

Social support rating scale (SSRS), designed by Xiao (1994), contains three dimensions, namely objective support, subjective support and utilization of support, totalling 10 items with a total score of 60. The total score is the sum of 10 items, and the score increases with growing social support. A score of less than 33 represents low levels of social support, a score of 33–45 represents normal levels of social support, and scores between 45–60 represent high levels of social support. Previous studies have proven that the internal consistency of each dimension of this scale was between 0.89–0.94 and that the total retest reliability was 0.92, whereas Cronbach's alpha of SSRS for the present study was 0.755.

2.2.4 | Short health scale

Short health scale (SHS) is a disease-specific scale used to measure the impact of inflammatory bowel disease on patients' health-related quality of life. This scale was developed by Swiss scholar Henrik and other academics (Hjortswang et al., 2006; Iglesias et al., 2009), and it laid a foundation for the Chinese version developed by Zhu et al. (2018). The Chinese version of the scale includes questions concerned with symptoms, functions, worry and general well-being. The score of every question ranges from 0–100, totalling 400. It was identified that patients with high health-related quality of life

exhibited lower SHS scores compared with patients with low life quality. A study reported that Cronbach's alpha of the Chinese version of SHS among patients with Crohn's disease (CD) and ulcerative colitis (UC) were 0.887 and 0.914, respectively. Cronbach's alpha of SHS in the present study was 0.862.

2.3 | Statistical analyses

Microsoft Excel software was used for data entry and database establishing. Statistical analyses were conducted using the Statistical Package for SPSS 22.0 (IBM, Armonk, NY, USA). All data were collected and checked by two researchers independently. Descriptive statistics used frequency and percentage, whereas inferential statistics was performed using mean, standard deviation or median and percentile. Univariate analyses were performed for each parameter by using t test, analysis of variance, non-parametric Mann–Whitney U test and Spearman correlation analysis. Multiple linear regression analysis with the stepwise method was conducted to find independent factors associated with resilience. The entry criterion was 0.05 (α in = 0.05), and the removal criterion was 0.10 (α out = 0.10). In this study, differences were indicated as statistically significant when $p < .05$.

2.4 | Ethic issues

The study was conducted in strict accordance with the regulations of the Declaration of Helsinki and was approved by Ethics Committee of hospital (Number: 201908666). Each participant was informed of the purpose and procedure and other details of this study at the beginning, and participation was voluntary. The participants were entitled to leave at any time without explanation. In addition, each participant signed consent forms approved by the institutional review board.

3 | RESULTS

3.1 | Characteristics

Among the 249 participants with IBD, 34 had ulcerative colitis (13.7%) and 215 Crohn's disease (86.3%). Moreover, the IBD patient group consisted of 183 male participants (73.5%) and 66 female participants (26.5%), and their ages ranged from 14–69, with the mean age being 33.14 ± 11.50.

3.2 | Score of resilience among the IBD patients

As shown in Table 1, the total resilience score of the participants was 67.39 ± 14.44, the score of self-management on the disease dimension was 11.37 ± 2.76, active response to difficulty was 14.73 ± 4.24,

TABLE 1 Score of resilience among the IBD patients ($\bar{x} \pm s$, 249)

Variables	Range	Score($\pm SD$)	Mean($\pm SD$)
Total	0–100	67.39 ± 14.44	
Self-management on disease	0–16	11.37 ± 2.76	2.84 ± 0.92
Active response to difficulty	0–24	14.73 ± 4.24	2.46 ± 0.93
Positive cognition	0–20	13.49 ± 3.99	2.70 ± 1.09
Emotional regulation	0–16	10.22 ± 2.92	2.55 ± 0.90
Family support	0–12	9.84 ± 2.49	3.28 ± 0.96
Other patients' support	0–12	7.74 ± 2.20	2.58 ± 0.99

TABLE 2 Score of SHS of the IBD patients, Median (P_{25}, P_{75})

	Score, Median (P25, P75)	
Scales	UC ($N = 34$)	CD ($N = 215$)
Symptoms	45 (20, 60)	40 (20, 50)
Function	50 (27.5, 80)	40 (20, 60)
Worry	55 (40, 90)	60 (30, 80)
General well-being	50 (30, 70)	40 (20, 60)

Abbreviations: CD, Crohn's disease; UC, ulcerative colitis.

positive cognition was 13.49 ± 3.99, emotional regulation was 10.22 ± 2.92, family support was 9.84 ± 2.49, and other patients' support was 7.74 ± 2.20. Strikingly, the highest score among the mean scores of items was in the family support dimension, whereas the lowest was in the active response to difficulty dimension.

3.3 | Score of SSRS and SHS of the IBD patients

The total SSRS score of IBD patients was 37.52 ± 7.73. More specifically, the scores for the objective support dimension, subjective support and utilization of social support were 7.97 ± 2.67, 22.24 ± 5.44 and 7.32 ± 1.86, respectively. The mean score for the subjective support dimension was the highest, followed by the objective support and utilization of social support. The SHS score among IBD patients is shown in Table 2.

3.4 | Correlation of resilience with social support and SHS

The results illustrated that the total score of resilience had a significant and positive correlation with utilization of social support ($r = .224$, $p < .01$), but a significant and negative correlation with SHS ($r = -.302$, $p < .01$) and its four dimensions ($r = -.219 \sim -.278$) (see Table 3).

TABLE 3 Analysis of correlation of resilience with social support and SHS (N = 249)

Items	Symptoms	Function	Worry	General well-being	SHS	RS	Subjective support	Objective support	Utilization of social support
Function	.685[**]								
Worry	.505[**]	.675[**]							
General well-being	.644[**]	.631[**]	.577[**]						
SHS	.801[**]	.890[**]	.836[**]	.830[**]					
RS	−.276[**]	−.264[**]	−.219[**]	−.278[**]	−.302[**]				
Subjective support	.039	−.021	−.057	−.062	−.029	−.024			
Objective support	.062	.035	−.059	−.043	−.001	−.019	.423[**]		
Utilization of social support	−.142[*]	−.167[**]	−.248[**]	−.156[*]	−.210[**]	.224[**]	.190[**]	.199[**]	
Total score of SSRS	.026	−.009	−.114	−.076	−.051	.031	.665[**]	.918[**]	.430[**]

*p < .05; **p < .01.

3.5 | Effect of demographic statistical data on resilience

The results of univariate analysis demonstrated that there was a significant difference in total scores of resilience in IBD patients in terms of different place of residence (Table 4). The regression equation demonstrated that living in the countryside and utilization of social support were significant predictors of resilience and that they could explain 7.7% of total variance of resilience (Table 5).

4 | DISCUSSION

In this study, results revealed that the resilience score of individuals suffering from IBD was 67.39 ± 14.44. The result was consistent with the research of Li et al. (2017) (64.87 ± 14.84). The finding that the score for family support was the highest among the dimensions was consistent with Bernhofer's findings (Bernhofer et al., 2017)), which suggests that family support for IBD patients is relatively strong and that they are capable of handling stress in the face of the condition. The vast majority of patients regarded family as the primary source of their resilience. With regard to the lowest score of active response to difficulty dimension, evidence suggested that IBD patients may have difficulty in accepting the condition and were pessimistic about treatment and life since they were at their prime when suffering from the disease (Gracie et al., 2017)). Moreover, the causes of IBD are scarcely understood, and no specific treatment method has been found. When the condition worsened, a considerable level of medical care service was required. Several studies have shown that the IBD patients cope negatively with the disease due to economic problems, working pressure, individual health and concern about future life (Sajadinejad et al., 2012; Yamabe et al., 2019). Lewis Kylee's study (Lewis et al., 2019) revealed that the incidence of depression in IBD was three to five times higher than that in general population, whereas IBD patients' anxiety was four to six times higher. It was highly likely that depression and anxiety were

discovered at least five years earlier than IBD, which to a large extent weakened the abilities of psychological adjustment, emotional regulation and active response to the disease (Keefer & Kane, 2017). Furthermore, emotional regulation is a kind of emotional coping approach. Given a significant and positive correlation between positive emotion and resilience (Tugade & Fredrickson, 2007), the patients' low level of resilience in response to difficulties might have a bearing on the inadequacy of positive psychological qualities and resources.

It is important that medical nurses relieve patients' depression and pay much more attention to their psychological qualities and access to resources, thus boosting patients' confidence in response to the disease and strengthening resilience in the face of difficulties. As a result, the psychological resilience level of the IBD patients may improve. It may be said that IBD patients' capabilities of emotional control and active response to difficulty should be elevated.

This study results revealed that the total score of social support was 37.52 ± 7.73, which was lower than that of Li et al. (2017) (39.68 ± 7.50) and Zhu et al. (2018) (39.89 ± 7.26) as well as the national norm of China (44.34 ± 8.38). Surprisingly, the objective support dimension and utilization of social support scores of the IBD patients were relatively low, which contains social expectations and Confucian ideas. Some patients from our study (data not shown) reasonably believed that they were a heavy burden on their family because of recurrent attacks, frequent use of medical care service and the restraints on normal life. Regarding illness, the psychological changes of individuals are largely determined by cultural beliefs, which affect their behaviour in seeking help (Kleinman, 1988). In addition to cultural influence in seeking help, behaviour is likely influenced by obvious differences in the scope of out-of-pocket expenses and the ability of seniors and their families to pay (Albanese et al., 2011). Hence, they were unwilling to convey negative emotions to others and appropriately express inner emotional demands, with the majority leaving their emotions unexpressed and their demands unmet. Furthermore, some literature has suggested that Confucian ideas of "benevolence" and "courtesy" in Chinese culture meant that Chinese were inclined to suppress their inner emotion and express stability and tolerance

TABLE 4 Results of univariate analysis of the effect of demographic statistical data on resilience ($N = 249$)

Variables	Frequency N (%)	Total score	t/F/H	p
Gender				
Male	183 (73.5)	67.35 ± 14.16	−0.065	.948
Female	66 (26.5)	67.48 ± 15.30	0.182	.947
Age				
<20	31 (12.4)	67.84 ± 11.62		
20–29	66 (26.5)	67.59 ± 15.95		
30–39	86 (34.5)	66.43 ± 14.58		
40–49	42 (16.9)	68.64 ± 13.92		
≥50	24 (9.6)	67.46 ± 14.72		
Disease subtype				
UC	34 (13.7)	67.21 ± 14.41	−0.078	.938
CD	215 (86.3)	67.41 ± 14.48		
Medical payment				
Self-paying	114 (45.8)	68.5 (57	2.325	.313
Health insurance	92 (36.9)	68 (58, 78.75)		
Other	43 (17.3)	64 (55, 71)		
Education				
Primary school	13 (5.2)	64.54 ± 15.10	0.377	.825
Junior school	43 (17.3)	65.63 ± 14.95		
High school or vocational school	73 (29.3)	67.71 ± 13.23		
Junior college	57 (22.9)	67.89 ± 13.43		
Above university	63 (25.3)	68.33 ± 16.36		
Marital status				
Single	89 (35.7)	69.44 ± 14.25	2.929	.055
Unmarried	155 (62.2)	65.89 ± 14.38		
Divorced	5 (2.0)	77.2 ± 14.41		
Place of residence				
City	112 (45.0)	71.01 ± 13.74	4.890	.003
Township	44 (17.7)	66.09 ± 12.00		
Rural	87 (34.9)	63.86 ± 15.45		
Change of residence	6 (2.4)	60.33 ± 15.02		
Annual income (CNY)				
Below 30,000	70 (28.1)	65.20 ± 14.81	1.158	.330
30,000–50,000	93 (37.3)	67.65 ± 14.63		
50,000–100,000	56 (22.5)	69.36 ± 15.19		
100,000–200,000	23 (9.2)	66.00 ± 10.27		
Above 300,000	7 (2.8)	74.57 ± 12.42		
Prior surgery				
Not treated	152 (61.0)	67.16 ± 15.45	−0.324	.746
Treated	97 (39.0)	67.74 ± 12.77		
Hospitalization				
Frequency none	27 (10.8)	67.48 ± 14.40	0.595	.553
1–2 times	79 (31.7)	68.80 ± 14.03		
Above 3 times	143 (57.4)	66.59 ± 14.71		
Smoking				

TABLE 4 (Continued)

Variables	Frequency N (%)	Total score	t/F/H	p
Never smoking	164 (65.9)	66.80 ± 14.54	1.134	.324
Ex-smoker	59 (23.7)	67.24 ± 13.96		
Smoker	26 (10.4)	71.38 ± 14.83		
Drinking				
Never drinking	147 (59.0)	67.64 ± 14.49	0.384	.682
Ex-drinker	79 (31.7)	66.39 ± 14.08		
Drinker	23 (9.2)	69.17 ± 15.74		

Abbreviations: CD, Crohn's disease; CNY, Chinese Yuan; UC, ulcerative colitis.

TABLE 5 Results of analysis of multiple linear regression (N = 249)

Dimensions	Factors	Regression coefficient	Standard error	Standardized regression coefficient	t	p
Total score of resilience	(Constant)	56.797	3.785		15.005	.000
	Utilization of social support	1.657	0.481	0.214	3.445	.001
	Countryside	−4.403	1.875	−0.146	−2.348	.020

Note: Living in the city was used as reference group of residence.

in the face of psychological distress and pressure. Patients should be encouraged to share their feelings and seek professional help. Researchers focus on the unique traditions of different countries (Luo et al., 2019). Some studies have indicated that social support was a predictor of levels of anxiety and depression and that sound social support could not only reduce patients' psychological distress but also strengthen their capacity to deal with stress and improve mental health (Dour et al., 2014; Jeong et al., 2016). Medical nurses have important responsibilities in terms of paying close attention to patients' emotional demands, encouraging them to communicate with each other, expressing their inner feelings, engaging in group activities, confiding their worries to others and asking for assistance from individuals or groups and helping them to create an atmospheres of sound social support. The nurses can not only assess the patient's life environment and incite them to take part in their own disease management but can also educate patients, their family and friends about IBD to raise awareness of the disease (Luo et al., 2019).

In this study, SHS scores among IBD patients was in line with previous studies, such as Stjernman et al. (2008). The low SHS scores of affected patients have been found to be related to the long course of disease, recurrent attacks, persistent disease-related stress, suffering from depression, anxiety and somnipathy, social withdrawal, weakened social ability and heavy economic burden as well as decreased quality of life (Jelsness-Jorgensen et al., 2012). One solution could involve medical nurses adopting methods of relieve stress and providing opportunities for mutual learning and communication by regularly holding conversations, developing diversified health education activities and encouraging not only patients but also their families to participate in those activities. In addition, medical nurses

should provide patients with emotional support and consulting support to comfort them so that they can positively pursue a higher health-related life quality.

The SHS score was negatively correlated with resilience (Table 3): that is to say, those patients who have high resilience had high quality of life. It may be partly because the patients who have high resilience are capable of maintaining a positive attitude to challenges, overcoming difficulties and achieving established goals or partly because those who have low resilience lack the confidence and ability in addressing problems and tend to be depressed and anxious. The quality of life was found to be closely related to psychological state and condition (Alizadeh et al., 2018). Negative responses, depressed mood, concealed condition, distance with others, repeated medical treatment, economic burden and limited social functions may lead to deteriorated psychological health and extensive mental trauma. Thus, patients tend to fear the condition and are unsatisfied with their health, which gives rise to lower-than-normal quality of life. This study suggested that more attention should be paid to the psychological status of patients affected and also that patients should be encouraged to share their difficulties, accept themselves and seek effective support and assistance from others so that their resilience level can be increased, their social competence strengthened and their condition and quality of life improved.

In this study, results demonstrated that living in the countryside was a significant predictor of lower resilience among participants. Similarly, Li et al. (2017) reported that patients living in the city had higher scores of psychological resilience than those living in the countryside. This could be explained by the fact that rural populations had no access to sound hospital environments and adequate available medical resources compared to urban citizens.

Furthermore, residents in cities have multiple channels to access various kinds of information, including the causes, treatment, development and recovery of the disease, so as to reduce the level of disease uncertainty. Research has shown that patients with low level of disease uncertainty have higher level of resilience (Kyungsuk and Kyunghee, 2012). Therefore, more attention should be paid on IBD patients living in the countryside.

This study has revealed that the total resilience score was significantly and positively correlated with utilization of social support, which was consistent with results in Rini et al. (2011). The utilization of social support was identified as an influential factor for resilience, which means that the IBD patients who exhibited a higher score for utilization of social support had higher levels of resilience compared with those who had lower scores. A previous study conducted by Ozbay et al. (2007) found a significant and positive correlation between subjective support and resilience. Some resources, including a large group of specialists, professional online platforms, such as the China Crohn's & Colitis Foundation (CCCF, which is Love in Prolongation of Inflammatory Bowel Disease Foundation for short), IBD-related applications and patient groups, as well as hospital and social service agencies, were found to be main sources of social support for IBD patients (Chen, 2018; Kamp et al., 2019). Sound social support, which provides individuals with positive emotional experience and stable social reward, may be beneficial in promoting their resilience and shaping their positive psychological qualities (Bolger & Amarel, 2007). Another related study (Campbell-Sills et al., 2006) found that individuals with high resilience could make use of various social support resources to strengthen response capacity, relieve psychological stresses, cultivate positive qualities, seek social resources and discover positive energy, thus increasing their resilience.

There are limitations of this study, the small sample size from a single centre limited the credibility of the findings. Therefore, data from multiple centres might be needed for further verification. Moreover, the direct or indirect influence of each factor on mental resilience should be deeply analysed through path analysis. Intervention measures for influencing factors of mental resilience in IBD patients and exploring their effectiveness should be further developed in the future.

5 | CONCLUSIONS

The current study revealed that the resilience level of BD patients should be increased and that place of residence and utilization of social support were critical factors affecting resilience. Medical nurses should strengthen the interventions applied to patients living in the rural during the treatment process. Furthermore, it also showed that the more social support, the higher their resilience level. However, resilience played a vital role in maintaining the psychosomatic health of IBD patients. This study suggested that measures to improve the IBD patients' emotional regulation, enhance the capacity to actively cope with difficulties and increase social support as well as utilization of social support should be put in place so as to boost their resilience, control their condition physiologically, psychologically and socially and promote their quality of life.

CONFLICT OF INTEREST

No conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

Study conception and design: WWD and QHZ. Data collection: EL. Data analysis and interpretation: LZ. Drafting of the article: YFZ and WWD. Critical revision of the article: JP and LZ. All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (https://www.icmje.org/recommendations/)]: substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; drafting the article or revising it critically for important intellectual content.

ETHICAL APPROVAL

The study was conducted in strict accordance with the regulations of the Declaration of Helsinki and was approved by Ethics Committee of hospital (Number: 201908666). Objects were informed of the purpose and procedures of this study and were entitled to leave at any time without answering. In addition, each object, willing to be enrolled in, also signed an informed consent before the study was began. All participants gave informed consent for the research and that their anonymity was preserved.

DATA AVAILABILITY STATEMENT

All data generated or analysed in this study are included in this article. And the raw data that support the results of this study are available from the corresponding author upon a reasonable request.

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