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Study of Alexithymia and Stigma in Patients with Inflammatory Bowel Disease

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Abstract: Objective: To investigate the current status and correlation between alexithymia and stigma in patients with inflammatory bowel disease (IBD). Methods: A total of 84 patients with inflammatory bowel disease (IBD) attending the gastroenterology department of a tertiary care hospital in Wuhan, Hubei Province, China, from December 2022 to May 2023 were selected method as the study population by handy sampling. The General Information Questionnaire, Toronto Alexithymia Scale, and Social Impact Scale were used for conducting questionnaires on them. Results: The total score of alexithymia in patients with inflammatory bowel disease was (60.67±8.19). The results of the correlation analysis showed that there was a significant positive correlation between the alexithymia and the stigma of patients with IBD, with correlation coefficients of ($r=0.37$, $P<0.01$). The results of regression analysis showed that stigma was an influential factor in alexithymia. Conclusion: Patients with inflammatory bowel disease have alexithymia and stigma, and alexithymia is significantly positively correlated with stigma, and stigma affects alexithymia.

Keywords: Inflammatory Bowel Disease; Alexithymia; Stigma.

1. Introduction

Inflammatory bowel disease (IBD) is a chronic non-specific inflammatory disease with diarrhea, abdominal pain, and bloody stools as the main symptoms. In recent years, the incidence of IBD in China has shown an increasing trend. Studies in the International Journal of Digestive Diseases and the Journal of Practical Medicine[1][2] have shown that IBD is already a common disease in China, with a 248.1% increase in prevalence from 2001 to 2010 compared to the previous decade, and is expected to continue to rise 4.29 times by 2025. Patients with IBD are often embarrassed by incontinence, and in severe cases, a series of complications such as gastrointestinal hemorrhage, perforation, obstruction, fistula, etc.[3] . In most cultures, symptoms such as incontinence that are difficult to care for oneself are often difficult to talk about, and the recurrent, persistent, and concealable nature of the condition makes patients with IBD more likely to develop a sense of stigma[4]. Stigma is a stigmatizing, discriminatory, and rejection experience that occurs when an individual suffers from a disease.[5] Foreign scholars have found that more than 84% of IBD patients have a presence of stigma.[6] The study found that more than 84% of IBD patients are with stigma. Domestic research on stigma is mainly focused on psychiatric and infectious diseases.[7][8] However, there is a lack of reports on patients with inflammatory bowel disease. Due to the different environments and cultural backgrounds at home and abroad, the stigma status of the IBD population in China may also be different.

Stigma often accompanies the emergence of alexithymia. Alexithymia refers to an individual's difficulty in emotional cognition and experience, characterized by deficits in emotional cognition and a lack of ability to disclose external attitudes, feelings, desires, and intentions[9][10]. The disorder has many adverse effects on patients, and research abroad has shown that it is more common in patients with IBD.[11] IBD patients are more prone to negative emotional experiences such as low self-esteem and increased stigma due to social discrimination and rejection, as well as delayed thinking and psychomotor activity and reduced volitional activity, making it difficult for them to effectively identify somatic and psychological symptoms and to accurately express their feelings. The disorder of emotional expression becomes more and more serious. There is a close relationship between stigma and affective disorders. In China, there are few studies on this population, especially on the relationship between alexithymia and stigma. This study aimed to understand the current status of alexithymia and stigma in IBD patients and their correlation, to provide a basis for targeted interventions and improve the quality of life of patients.

2. Objects and Methods

2.1. Object

From March 2023 to May 2023, 84 patients with inflammatory bowel disease in a tertiary care general hospital in Hubei Province, China were selected as the study population by handy sampling method. Inclusion criteria: 1. those who met the diagnostic criteria for idiopathic inflammatory bowel disease in the Chinese Journal of Inflammatory Bowel Disease and were aware of their condition as diagnosed by clinicians; 2. those aged >=16 years; 3. those with normal comprehension and informed consent. Exclusion criteria: 1. participants with physical illnesses other than inflammatory bowel disease and its complications; 2. participants with or who had suffered from mental illness; 3. participants with a family history of mental illness; 4. participants who for some reason could not answer truthfully. A total of 86 questionnaires were distributed in this study, and 84 valid questionnaires were recovered according to the inclusion criteria, with an effective rate of 97.67%,

including 34 cases of males and 50 cases of females; 72 cases in Hubei province and 12 cases outside Hubei province of residence; 62 patients with disease activity in remission and 22 cases in the active phase.

2.2. Method

2.2.1. General Information Questionnaire

A general questionnaire, developed by the researcher himself, asked for basic demographic and disease-related information. It included: 1. demographic information: gender, age, and residence of the subject; 2. disease-related information: the subject's current level of disease activity in IBD, and whether the subject had undergone surgery. 3. relevant questions used to screen for inclusion and exclusion criteria.

2.2.2. Toronto Alexithymia Scale (TAS-20)

The Chinese version was developed by foreign psychologist Taylor in 1984 and revised by Yuan Yonggui and other scholars, with good reliability and validity. The scale includes three dimensions: difficulty in emotion recognition, difficulty in emotion expression, and extroverted thinking, with a total of 20 items, using the Likert five-point scale, in which 5 items, including 4, 5, 10, 18, and 19, are reverse scored, and the total score is between 20 and 100. A total score of >=61 was considered alexithymia, 52-60 was considered suspected alexithymia, and <=51 was considered a non-alexithymia. The higher the score, the more severe alexithymia is. Some studies have demonstrated that the internal consistency coefficient of the scale was 0.79 [12].

2.2.3. Social Impact Scale (SIS)

The Chinese version of the scale, developed by foreign scholars Fife and Wright in 2000 based on marker theory and Chine seized by Taiwanese scholars Pan et al, was used. The scale includes 24 entries and 4 dimensions, namely social exclusion, economic discrimination, intrinsic shame, and social isolation. Among them, social exclusion and economic discrimination denote perceived stigma and discrimination, while intrinsic shame and social isolation denote actual stigma and discrimination. The scale is scored on a 4-point scale, with higher scores indicating greater perceived stigma and more discrimination. A total score of >=70 indicates a sense of stigma, where less than 48 is a low level, 48-72 is a medium level, and 72 or more is a high level. Some studies have demonstrated that the internal consistency coefficient of the total scale is 0.916, and the internal consistency coefficients of the 4 dimensions are 0.708~0.835[12].

2.3. Statistical Processing

The data were analyzed by SPSS 26.0. The data were analyzed by descriptive analysis, independent two-sample *t*-test for the demographic differences of the alexithymia, Pearson correlation analysis for the correlation between stigma and alexithymia, and linear regression analysis for the analysis of the factors influencing the alexithymia, with P<0.05 indicating a statistically significant difference.

3. Results

3.1. Alexithymia in Patients with Inflammatory Bowel Disease (TAS-20)

The descriptive statistics of the total score of alexithymia in IBD patients showed that the total score of alexithymia in IBD patients was 60.67±8.19, and 48 of them were greater than 61, accounting for 57% of the total number of subjects, i.e. 57% of the subjects in this study had alexithymia. There was no significant difference in the total score of alexithymia between males and females in IBD patients (p>0.05); for patients with different disease activity and for patients who had or had not undergone surgery, their scores on the TAS-20 scale were not significantly different (p > 0.05).

3.2. Stigma in Patients with Inflammatory Bowel Disease

Patients with IBD had a stigma score of 62.49 ± 9.46, with 17 patients (20.24%) with a high level of stigma, 64 patients (76.19%) with a medium level, and 3 patients (3.57%) with a low level, and the stigma score was significantly higher than the median of 60 (p < 0.05).

3.3. Analysis of the Correlation between Alexithymia and Stigma in Patients with Inflammatory Bowel Disease

The total SIS score of patients with inflammatory bowel disease was correlated with the total score of TAS-20, and the results are shown in Table 1, where the stigma of patients with IBD was significantly positively correlated with alexithymia (where r=0.37, p<0.01).

Table 1. Correlation analysis of alexithymia and stigma in patients with IBD

	Stigma	Alexithymia	Difficulty in emotion recognition	Difficulty in expressing emotions	Extroverted thinking
Stigma	1				
Alexithymia	0.37**	1			
Difficulty in emotion recognition	0.28**	0.78**	1		
Difficulty in expressing emotions	0.34**	0.62**	0.31**	1	
Extroverted thinking	0.16	0.67**	0.24*	0.10	1

Note: * denotes p<0.05, ** denotes p<0.01

3.4. Regression Analysis of Alexithymia on Stigma in Patients with Inflammatory Bowel Disease

The results of the linear regression analysis with the total score of TAS-20 as the dependent variable and the total score of SIS as the independent variable in patients with inflammatory bowel disease are shown in Table 2. Stigma is an influential factor in alexithymia.

Table 2. Effect of stigma on alexithymia in patients with IBD

	R	R^2	F	β	t	p
Stigma	0.37	0.14	12.80**	0.367	3.58	<0.01

4. Discussion

4.1. Alexithymia in Patients with Inflammatory Bowel Disease

In this study, 57% of patients with inflammatory bowel disease had alexithymia. The total score and the mean score of each dimension were greater than those of the normal sample group measured by Yuan Yonggui [14] et al. In a return visit to the measured IBD patient group and physicians in this specialty, it was indicated that IBD patients mainly showed conservative interpersonal relationships, could not express their inner feelings accurately in words, were not good at describing their thoughts, could not distinguish between somatic feelings and emotional states. Patients tended to focus on describing somatic discomfort and could not talk about their current feelings. This is consistent with Factor 1 (difficulty in emotion recognition) and Factor 2 (difficulty in expressing emotions) of the TAS scale and is corroborated by the fact that the group of IBD patients tested showed high scores on both factors. It may be because patients with inflammatory bowel disease are prone to symptoms that affect their physical and mental health, such as fecal incontinence, diarrhea, and blood in stool, due to complications such as intestinal ulcers, intestinal perforation, and anal fistula, and because the causes of the disease are unknown and poorly treated, most of the somatic symptoms involve personal privacy, and patients often have difficulty talking about the parts of the body where they have the disease. The initial manifestations of inflammatory bowel disease are diarrhea and weight loss, which leads patients to confuse disease production with their irregularities in work and rest and other reasons, making patients reluctant to talk about these symptoms with their families and doctors. Patients often choose to internalize the abnormalities that occur in their bodies and are reluctant to express their feelings, and under long-term emotional repression, their psychological burden increases, and their ability to express themselves decreases, so the level of alexithymia is higher. Therefore, healthcare professionals should fully understand the current situation of alexithymia in patients with inflammatory bowel disease, give effective intervention guidance, actively educate patients about the generation of the disease and how to live during the disease, and guide patients and their families to look at the disease with a more tolerant and open mind, to reduce the patient's level of alexithymia and improve their quality of life.

4.2. Stigma Exists in Patients with Inflammatory Bowel Disease

In this study, we found that patients with inflammatory bowel disease have a high level of stigma, which may be because it is difficult to be understood when patients with inflammatory bowel disease will keep running to the toilet, farting frequently, and being incontinent, and patients are easily embarrassed and feel very significant embarrassment and loneliness. Ruan Jiayin [15] et al. found that the degree of negative emotions such as anxiety and depression were closely related to the patient's disease site in the mental health status of patients with bowel disease, and patients with active disease had negative psychology such as sadness, fear, anxiety, self-blame, shame, and low self-esteem. Therefore, patients with IBD have a high level of disease stigma.

4.3. The Relationship between Stigma and Alexithymia

This study showed a significant positive correlation between stigma and alexithymia, which is consistent with the findings of Wang Xuecheng et al.[16] When patients are in a difficult situation, they control their emotions by suppressing them, i.e. by internalizing shame, avoiding the thoughts and behaviors of others, thus blaming themselves for the disease, keeping it a secret, and not wanting to communicate with others, which is one of the possible causes of alexithymia. Mantani et al.[17] found that the more social support cancer patients felt after surgery, the higher the emotional sharing. Patients were able to identify their own emotions through effective communication, which in turn reduced the incidence of alexithymia. It is predicted that patients' stigma and alexithymia interact with each other. The positive correlation between stigma and alexithymia may also be due to the uncertainty that the patient's disease is currently incurable and accompanied by the risk of severe deterioration, which causes the patient to become pessimistic and isolated, social interactions become hindered, and the social isolation felt by the patient increases, so there is a correlation between stigma and alexithymia.

Miyahara[18] in a study of the relationship between alexithymia and psychosomatic disorders has shown that alexithymia is correlated with high disease activity in patients, so healthcare professionals can use mental health education interventions, relaxation training, and increasing residents' awareness of the disease to reduce patients' stigma and improve their ability to cope with the disease and avoid alexithymia.

The results of this study showed that stigma is an influential factor in alexithymia in patients with inflammatory bowel disease, which may be related to the prevalence of self-shame and self-depreciation in patients with inflammatory bowel disease. Patients' lives are affected by the physical problems brought about by the disease and the long-lasting treatment of the disease, which makes their self-evaluation become lower and self-depreciation occurs. When patients feel the negative attitude and behavior of others toward them, they adopt self-protection to fight against the stigma of the disease, so they are reluctant to express their emotions and develop alexithymia. Therefore, for patients with stigma, healthcare professionals can give correct guidance to patients' illness perceptions to reduce their stigma and thus reduce their level of alexithymia.

5. Shortcomings and Improvements

Firstly, the sample selected in this study was relatively single, only one hospital patient group was selected, which is relatively limited in scope and may be affected by various aspects such as different geographical and human factors and different treatment methods in hospitals, etc. Attention should be paid to these problems in future studies to expand the scope of the study and ensure the accuracy of the results.

Second, most of the selected patient population were inpatients. The sample was not universal and may conflict with the results of similar studies by other scholars.

Finally, this study used the form of online distribution of questionnaires, which is difficult to foresee for the situation of the person who fills in the questionnaire, so the results are susceptible to the influence of the environment and emotions of the subjects at that time, leading to errors in the results. The

offline survey method can be adopted in future studies to reduce the error caused by the measurement.

6. Conclusion

(1) Patients with IBD have alexithymia.

(2) The alexithymia in IBD patients is correlated with stigma.

(3) Stigma can have an impact on alexithymia in patients with IBD.

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