

Influence Of Narrative Medicine-Based Health Education Combined With An Online Patient Mutual Assistance Group On The Health Of Patients With Inflammatory Bowel Disease and Arthritis

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Background: Inflammatory bowel disease arthritis (IBDA) threatens patients' physical and mental health. Therefore, patients need not only physical therapy, but also adequate health education and psychological support. This study was designed to explore the effect of health education based on narrative medicine combined with an online patient mutual assistance group that was based on the physical and mental health of patients with IBDA.

Methods: A total of 120 patients with IBDA were randomly divided into four groups (30 patients per group). Patients in the control group were given routine health education on the premise of routine treatment. The three treatment groups were given health education based on narrative medicine, online patient mutual assistance group intervention, or combined intervention. Depression, sleep, arthralgia, irritable bowel syndrome (IBS) symptoms, and inflammatory factors were measured and compared before and 1 month after the intervention.

Results: Before the intervention, no significant differences were observed in baseline data between the four groups. However, after the intervention, the physical and mental health of patients who received health education based on narrative medicine or online patient mutual assistance groups was improved. Our data showed that patients in the combined intervention group experienced a better outcome.

Conclusion: Narrative medicine-based health education combined with an online patient mutual assistance group is beneficial to the physical and mental health of IBDA patients. Taken together, this model needs to be further deepened and popularized in clinical practice.

Keywords: IBDA, narrative medicine, online patient mutual assistance group, health education

Background

Inflammatory bowel disease (IBD) includes ulcerative colitis (UC) and Crohn's disease. IBD is a non-specific, recurrent intestinal inflammatory disease that involves all segments of the digestive tract.¹ Patients with IBD suffer physical discomfort, which is often accompanied by depression, anxiety, sleep disorders, and other mental and psychological problems.²⁻⁴ IBD arthritis (IBDA) is arthritis associated with IBD, which is the most common parenteral manifestation of IBD. Roughly 15% to 20% of the patients with IBD may have arthralgia or arthritis. This may not only involve

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peripheral joints, which lead to pain and swelling in knee, ankle, shoulder, elbow, and wrist joints, but may also involve medial axis joints, which can cause sacroiliac arthritis and hip joint involvement. In addition, a small population of patients can develop ankylosing spondylitis.⁵⁻⁷ These patients not only suffer from digestive tract symptoms but also experience joint pain and limited movement, which may seriously affect their physical and mental health. Therefore, in addition to active drug treatment, attention should be paid to the mental health of IBDA patients and appropriate health education and humanistic care should be provided.

Integrating the concept of narrative medicine into health education to improve patients' physical and mental health may be effective. Narrative medicine is a medical model that in 2001 was proposed by Professor Rita Charon of the Columbia University.⁸ It emphasizes that medical staff listen to and respect a patient's story, including social and psychological roles conferred by diseases, metaphors of diseases, views on diseases, and their beliefs. Medical staff who fully sympathize with patients in their narratives will establish trust relationships, and reflect on their professional behavior. By listening to a patient's narrative, they absorb, explain, and respond to the patient's story, and thereby help the patient appropriately.^{9,10} As a supplement to evidence-based medicine, narrative medicine has been piloted in clinical practice and has become an important part of medical education.^{11,12}

In this study, narrative medicine was combined with an online patient mutual assistance group. Patient mutual assistance organizations are based on a group of patients with the same disease, which aim at promoting disease rehabilitation and helping each other. These groups are common in chronic, severe and rare diseases. Because the overall incidence of IBD is not high, patients usually have limited knowledge about the disease; therefore, disease uncertainty, depression and other negative emotions are stronger. Online patient mutual assistance organizations gather patients and provide a platform for patients to communicate. Although several studies have focused on psychological and behavioral interventions of IBD patients, at present, narrative medicine has not been applied in the health education of such patients.^{13,14} The purpose of this study was to explore the effects of health education based on narrative medicine combined with online patient support groups on factors such as depression, sleep, irritable bowel syndrome (IBS), arthralgia, and inflammatory factors in patients with IBDA.

Materials And Methods

Participants

The participants were 120 outpatients with IBDA who underwent treatment at several hospitals in the Guangdong Province, China between July 2017 and December 2018. The patients met the predetermined criteria for eligibility, which were as follows: 1) Each patient was diagnosed with IBDA and had joint symptoms. They knew their diagnosis and were able to provide informed consent and complete all questionnaires with full awareness of their diagnosis. 2) Each patient was between 18 and 70 years of age. 3) Each patient was measured by Montreal Cognitive Assessment (MoCA) and were identified that had clear thinking and no cognitive impairment. 4) The patients were prescribed mesalamine (2.0g/d). Exclusion criteria were as follows: Patients who suffered from other diseases that may affect the evaluation of the scale, polysomnography (PSG) results, and blood biochemical results. For example, patients with severe respiratory, liver, and kidney diseases affecting sleep, prostate diseases causing frequent nocturia, cancer, other osteoarthritic diseases, severe infectious diseases, Parkinson's and epilepsy, schizophrenia, and other mental diseases were included. The final evaluative sample consisted of 120 patients with IBDA (Figure 1).

Procedure

In this study, a randomized controlled trial in which data were collected pre- and post-intervention was conducted. All the 120 patients were numbered. Patients were randomly divided into four groups (1 control group and 3 research groups) by random number table. The demographic sociology information, depression, sleep, IBS, arthralgia, and inflammatory factors were measured and compared. Then, based on conventional drugs, patients in Group 1 were given routine health education and treatment guidance, patients in Group 2 were given health education based on narrative medicine, patients in Group 3 were asked to join an online patient mutual assistance group, and patients in Group 4 received narrative medicine-based health education combined with an online patient mutual assistance group. All 120 patients had a first visit and a subsequent visit, which were conducted face-to-face. In most cases, considering China's national conditions, the visits were within 5 min at a time. At 6 weeks after the start of the program, the physical and mental health indicators of the four groups were measured.

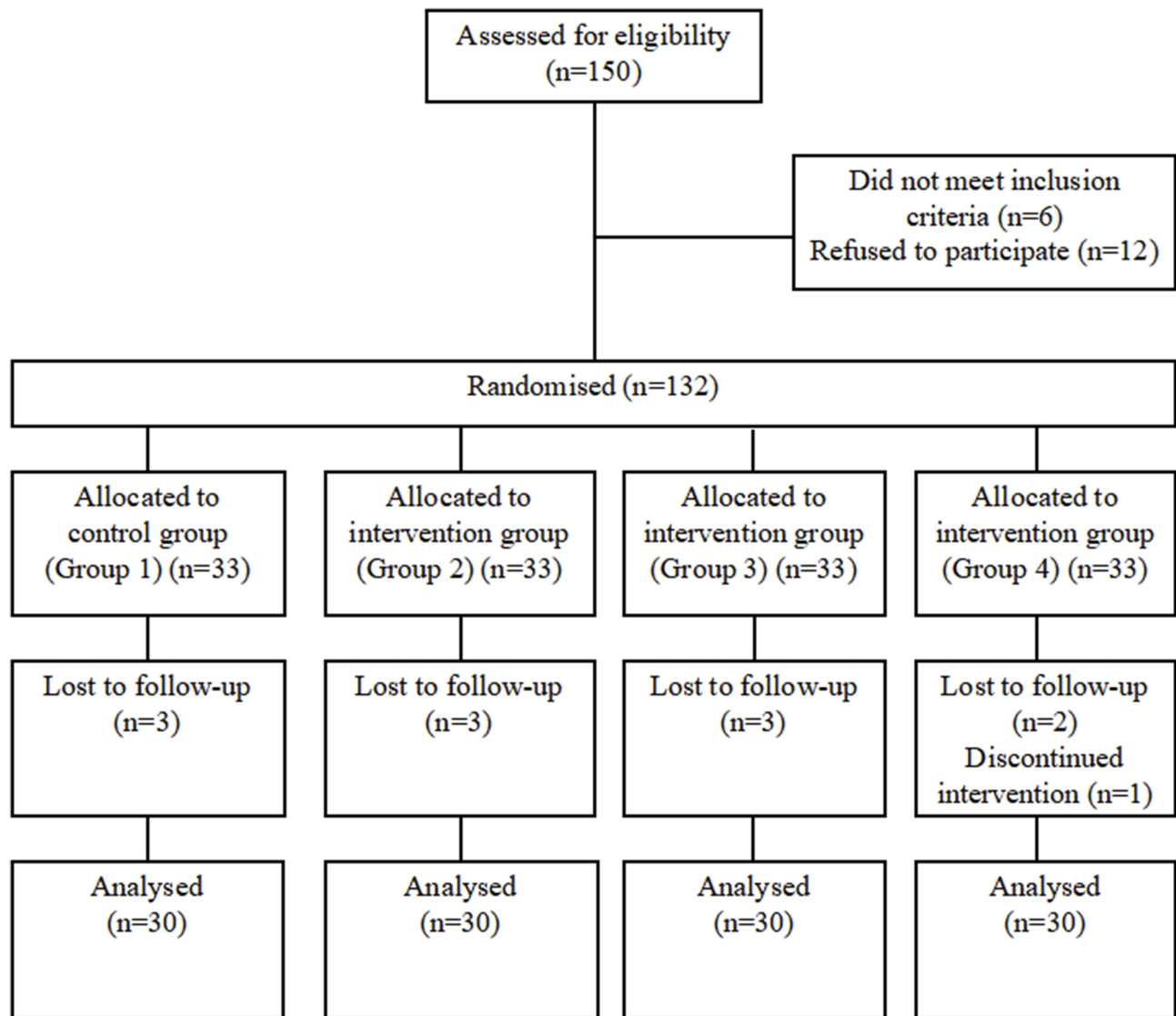


Figure 1 Flow chart of sample selection of 120 IBDA patients.

Narrative Medicine-Based Health Education

The program lasted for 4 weeks and involved three main steps: narrative telling, parallel charts writing and reflection, continuous narrative, and guidance. The narratives were divided into two parts: disease-centered narratives and illness-centered narratives. In Week 1, disease-centered narratives were carried out and dominated by attending doctors of the patients. The contents included disease overview, dietary guidance, rest activity guidance, medication guidance, inspection guidance, and treatment guidance. Patients could narrate about physical health-related issues and ask questions to doctors. This part lasted at least 30 mins. Next, illness-centered narratives dominated by patients were conducted.

The interview included: psychological status, personality and personality traits of a patient after illness, cognition of etiology, communication mode with others, expectation and confidence in treatment, work pressure, social interaction, social support and social capital, family economy, tendency of clinical decision-making, outlook on life and death, outlook on suffering, and outlook on medical treatment. In the interview, the doctor empathized with the patient, carefully listened to the patients' narratives and provided the patient with appropriate responses. During the conversation, doctors spread disease and treatment-related knowledge, guided healthy behavior, answered patients' questions, and appeased a patients' negative emotions. In addition, doctors discussed with patients how to face psycho-social problems. This part

lasted at least 30 mins. Then, the doctor wrote parallel charts, which was a supplement for the standard medical record, the content focused on the patient's suffering and experience. In the process of writing, doctors deepened their understanding of a patient's suffering and reflected on their self-practice to achieve patient-centered care. In Week 2 to Week 4, patients continued their narratives during their reexamination once a week. They talked about their physical and emotional changes and asked new questions. Based on understanding a patient's needs and self-reflection, doctors provided patients with more targeted health education, treatment guidance, and psychological counseling. In this program, all participating doctors received narrative medicine training before the start of the project.

Online Patient Mutual Assistance Group

Nurses set up Wechat Groups, and patients joined Wechat Groups and participated in online group discussions. Patients discussed and shared diseases, treatment and daily life, and comfort and helped each other. The Wechat group contained doctors, nurses, psychotherapists, and nutritionists. Patients' questions were gathered and answered twice a week. The program lasted 6 weeks.

Measures

Essential Information And Disease Condition

Patients' essential information and disease condition were obtained via medical record review, which included age, sex, disease type, and IBS.

Depression

The Hospital Anxiety and Depression Scale (HADS) was used to assess a patient's depressive mood. The HADS is a 14-item self-assessment scale, consisting of 7 items used to screen for anxiety (HADS-a) and 7 items used to screen for depression (HADS-d). Each item consists of a 4-point (0–3) Likert-type scale, and each subscale totals from 0 to 21, or from 0 to 42 for the two scales. Higher scores indicated more severe anxiety or depression.¹⁵ In previous studies, it was identified that the optimal cutoffs for both HADS-a and HADS-d were 8 or more, and for HADS-total this was 15.¹⁶ Participants were asked to choose their response for each question according to their actual circumstance in 1 month. Because the authors did not undergo a psychiatrist qualification, an underlying depression could not be diagnosed only by the scale. In this

study, only HADS-d was used to measure the depressive mood in patients. Currently, the scale is widely used to assess anxiety and depression in cancer patients. The scale has satisfactory reliability and validity.

Sleep

Sleep monitoring was performed in three groups by polysomnography. All patients were monitored by PSG throughout the night (at least 7 hrs). According to the international standard method, surface disc electrodes were used to synchronously record electroencephalogram (EEG) signals of six parts (F3-A2, F4-A1, C3-A2, O1-A2, O2-A1). Two surface electrodes were taken to record the electromyogram (EMG) of the chin. An electrode was placed at 1 cm above and below the lateral canthus to record eye movements of both the left and right eye. To measure sleep quality, sleep efficiency (SE), ie, ratio of total sleep time to bedtime was used.

Arthralgia

The degree of arthralgia in patients with IBDA was measured by a numerical rating scale (NRS). Pain intensity was described as 0–10. Higher numbers indicated a stronger sense of pain.¹⁷

Inflammatory Factors

Serum levels of IL-17, IL-22, IL-23, IL-35 T1, and IL-35 were determined by ELISA. An SM802 enzyme labeling instrument was used for determination. The kit was produced by Wuhan Doctor De Bioengineering Co., Ltd. (Wuhan, China) and the enzyme label instrument was from Shanghai Yongchuang Medical Devices Co., Ltd. (Shanghai, China).

Statistical Analyses

Epi Info version 3.1 (Centers for Disease Control and Prevention, Atlanta, GA, USA) was used for the entry and summary of the data. IBM SPSS Statistics, version 20 (IBM Corp., Armonk, NY, USA) was used to analyze the data. Data are expressed as Median and interquartile range (IQR). Kruskal–Wallis *H*-test was used to compare the indices between four groups. Mann–Whitney *U*-test was used to compare the two groups and the changes of indicators in each group before and after the intervention. Differences in frequency among groups were calculated using χ^2 test.

Table 1 Comparison Of Basic Demographic And Clinical Characteristics Of 4 Groups Of Subjects

	Group 1 n=30	Group 2 n=30	Group 3 n=30	Group 4 n=30	F/ χ^2	P
Age: mean (\pm SD)	35.48 \pm 4.96	37.22 \pm 5.34	36.85 \pm 4.58	38.46 \pm 6.18	1.608	0.191
Sex: Males, N (%)	16, 53.33%	18, 60%	17, 56.67%	18, 60%	0.375	0.945
Disease species: Crohn's disease N (%)	7, 23.33%	6, 20%	9, 30%	7, 23.33%	0.864	0.834
IBS: Yes N (%)	15, 50%	16, 53.33%	18, 60%	17, 56.67%	0.673	0.879

Results

Samples

A total of 120 patients took part in this research. No significant differences were observed in the basic demographic and clinical characteristics between the four groups. The results are summarized in Table 1.

Comparison Of Depression, Pain, Sleep, And IBS Between The 4 Groups

Data for depression, pain, sleep, and IBS between the patients in 4 groups are shown in Table 2. Firstly, when comparing between groups, at T1, there was no significant difference in all the four indicators between the four groups. At T2, comparing the four indicators of the four groups, the difference has statistical significance. The depression, pain and proportion of IBS patients of Group 4 were significantly lower than the other three groups while the sleep quality was significantly higher than the other three groups. Secondly, the indices of the same group of patients at different time points were compared. For Group 4, at T2, the depression, pain and proportion of IBS patients were significantly lower than T1 while the sleep quality was significantly higher than T1. However, for the other three groups, compared with T1, not all indicators have significant changes at T2.

Comparison Of Inflammatory Factors Between The 4 Groups

Comparison of inflammatory factors between the 4 groups is given in Table 3.

When comparing within each group, after medication and health education (T2), the IL-6, IL-17, IL-23 were decreased and none of the 4 groups showed changes in IL 35. When comparing between groups, at T1, no significant differences in baseline data were observed. At T2, IL-6, IL-17, and IL-23 in Group 4 were significantly lower when compared to that of Group 1, Group 2 and Group 3. However, for IL-35, no significant differences were observed between the 4 groups.

Discussion

This study confirmed that health education based on narrative medicine or an online patient mutual assistance group helped to reduce depression, insomnia, IBS symptoms, arthralgia, and proinflammatory factors in IBDA patients. In other words, the positive effect of health education based on narrative medicine combined with an online patient mutual assistance group was more significant than using a single method. The positive effect of narrative medicine on a patient's physical and mental health has been confirmed by previous studies. For example, the narrative medical intervention helped to improve the self-management and quality of life of COPD patients,¹⁸ reduced the depressive emotion level in patients with Parkinson's disease,¹⁹ reduced pain and improved well-being in cancer patients,²⁰ and reduced polypharmacy.²¹

Physical And Mental Health Of IBDA Patients

In this study, we demonstrated that despite receiving symptomatic treatment, patients with IBDA still manifested depression, sleep disorders, arthralgia, IBS, high levels of serum proinflammatory factors (IL-6, IL-17, IL-23), and low levels of anti-inflammatory factors (IL-35). The main reason for depression was that patients with IBDA were under high physical and mental pressure. Physically, patients suffered from digestive tract symptoms and arthralgia. Psychologically, because of the lack of awareness of the disease, they had more uncertainty about the disease, which led to negative emotions. Patients had serious sleep problems. The reasons may include the following: on the one hand, nocturnal gastrointestinal symptoms, arthralgia, high levels of serum inflammatory factors, and the use of glucocorticoids affected a patient's sleep.^{22,23} On the other hand, negative emotions, such as anxiety and depression led to insomnia.²⁴ Arthralgia was the most typical feature of IBDA patients, because patients often had peripheral joint lesions or central axis joint involvement.²⁵ Some patients have IBS symptoms. Systematic reviews have shown that

Table 2 Comparison Of Depression, Pain, Sleep And IBS Between The 4 Groups

	N	Depression T1	Depression T2	Pain T1	Pain T2	Sleep T1	Sleep T2	IBS N (%) T1	IBS N (%) T2
G1	30	15.12±2.86	13.01±3.02 ^{bcde}	5.56±1.18	1.13±0.26 ^{de}	73.28±12.25	73.55±10.98 ^d	15, 50%	13, 43.33% ^d
G2	30	13.98±3.23	11.24±2.98 ^{ade}	5.32±0.95	1.14±0.09 ^{de}	70.89±11.05	79.32±10.28 ^e	16, 53.33%	13, 43.33% ^d
G3	30	15.59±4.25	10.31±3.23 ^{ade}	6.01±1.86	1.09±0.76 ^{de}	72.17±13.01	74.45±11.92 ^d	18, 60%	16, 53.33% ^d
G4	30	14.21±2.86	7.66±1.25 ^{abce}	5.78±1.22	0.57±0.88 ^{abce}	69.01±10.58	81.66±12.12 ^{ace}	17, 56.67%	5, 16.67% ^{abce}
<i>f</i> / <i>χ</i> ²		1.538	19.92	1.357	6.396	0.729	3.324	0.673	9.338
TP		0.208	<0.0001	0.260	0.0005	0.537	0.022	0.879	0.025

Notes: ^aThe difference compared with Group 1 (P<0.05); ^bThe difference compared with Group 2 (P<0.05); ^cThe difference compared with Group 3 (P<0.05); ^dThe difference compared with Group 4 (P<0.05); ^eFor the same group, the difference compared with T1 (P<0.05).

Table 3 Comparison Of Inflammatory Factors Between The 4 Groups (Unit: pg/mL)

	N	IL-6 T1	IL-6 T2	IL-17 T1	IL-17 T2	IL-23 T1	IL-23 T2	IL-35 T1	IL-35 T2
G1	30	152.32±20.24	55.28±12.61 ^{bde}	335.38±22.21	305.45±17.69 ^{de}	621.88±34.56	398.54±28.67 ^{bcde}	46.76±11.63	48.87±15.43
G2	30	146.28±12.68	48.31±6.28 ^{ade}	331.26±19.98	298.77±20.87 ^{de}	614.25±31.79	358.65±29.63 ^{ade}	44.95±13.27	48.75±16.11
G3	30	148.44±15.27	52.5±12.37 ^{de}	342.44±25.12	301.33±16.35 ^{de}	606.28±40.76	367.34±33.25 ^{ade}	48.11±15.54	49.45±15.67
G4	30	155.42±21.73	40.72±9.88 ^{abce}	340.56±24.78	260.78±19.63 ^{abce}	611.46±29.98	289.77±30.61 ^{abce}	45.78±12.88	52.34±14.45
<i>f</i>		1.553	10.74	0.234	36.76	1.067	67.42	0.363	0.358
TP		0.205	<0.0001	1.444	<0.0001	0.366	<0.0001	0.780	0.783

Notes: ^aThe difference compared with Group 1 (P<0.05); ^bThe difference compared with Group 2 (P<0.05); ^cThe difference compared with Group 3 (P<0.05); ^dThe difference compared with Group 4 (P<0.05); ^eFor the same group, the difference compared with T1 (P<0.05).

the overall prevalence of IBS-like symptoms in IBD patients was as high as 39%.²⁶ This may be because in IBD, the brunt of immune-mediated injury was borne by the mucosal compartment, whereas in IBS, the mucosal compartment may play a role in initiating events.²⁷ Psychological stress can affect a patient's digestive system through the brain-gut axis and HPA axis.^{28,29} IBD patients often have negative emotions; therefore, IBS was more likely to develop. In addition, when compared with healthy individuals, IBD patients tend to have changes in serum inflammatory factors. They have higher levels of pro-inflammatory factors and lower levels of anti-inflammatory factors, which are the manifestations of inflammation. Therefore, appropriate health education and psychological and behavioral intervention are of utmost importance. Thus, we carried out the health education as described above.

The Effect Of Health Education Based On Narrative Medicine On Patients' Mental Health

Regarding mental health, this study confirmed that health education based on narrative medicine reduced depression and sleep disorders in IBD patients. This was mainly based on the following: first, in the narrative process, empathy between doctors and patients is achieved, and doctors understand the root causes of a patient's stress, distress, and sense of uncertainty.³⁰ Therefore, they can provide patients with corresponding answers, psychological counseling, and targeted health education. For example, in the patient's narrative, the doctor understands that because the patient's condition recurs repeatedly, and the course of the disease is longer, the patient is worried that he/she cannot be cured and fear death. In addition, a patient may lose patience and compliance because of frequent episodes of gastrointestinal symptoms. Doctors can further explain the patient's condition, discuss treatment plans with patients, and tell them how to regulate healthy behavior. Throughout the process, patients were given comfort, company and humanistic care. Therefore, the patient's negative emotions will be alleviated. Secondly, in the narrative process, mutual trust between doctors and patients is established, therefore a patient's compliance and self-efficacy are high, which is more conducive to rehabilitation.³¹ Physical rehabilitation directly contributes to the relief of negative emotions. For example, relief of arthralgia and gastrointestinal symptoms is more conducive to sleep and reducing depression. Thirdly, for patients, narration itself is the release of emotion and pressure. Because patients with chronic diseases often face changes in social status, social relations, economic difficulties, and

family relations, such as job adjustment or even separation and divorce due to illness. Therefore, patients often face multiple stresses that need to be released. By listening to and respecting a patient's story, patients can feel witness, concern, trust, respect and care, which is of great benefit to mental health.^{32,33} Depression is closely related to sleep. When the psychological burden of patients is reduced, the quality of sleep will improve.³⁴

The Effect Of Health Education Based On Narrative Medicine On Patients' Physical Health

Regarding physical condition, on the one hand, health education based on narrative medicine, as mentioned above, enabled patients to do better in self-disease management and adhere, thereby alleviating their illness. As a result, their IBS symptoms and arthralgia were alleviated and serum proinflammatory factors were reduced. On the other hand, narrative medicine has shown to affect the physical symptoms of patients by affecting their psychological state.³⁵ The relationship between psychology and digestive tract symptoms is mainly through the brain-gut axis. The brain-gut axis is bidirectionally regulated. The principle of the brain-gut axis is as follows: abnormal mental stimulation and excessive emotional fluctuation will affect the function of the autonomic nervous center (nucleus) of the gastrointestinal tract, and subsequently affect the function of the gastrointestinal tract. Changes in brain function can also cause gastrointestinal mucosal inflammation through the endocrine and immune systems, cause gastrointestinal motility disorders, and gastrointestinal hypersensitivity to stimulation, and cause and aggravate clinical symptoms of the gastrointestinal tract. Conversely, changes in the functional status of the intestinal tract can also be caused by gastrointestinal mucosal inflammation, through the nervous and blood circulation system to affect brain function to trigger psychological and emotional changes.^{36,37} Therefore, if patients achieve a higher level of mental health through narrating, the interaction between brain and intestine will enter a virtuous circle. Regarding arthralgia, the interaction between emotion and pain has been confirmed in many studies.³⁸ The main mechanism is that patients with negative emotions, such as depression tend to have lower levels of 5-HT and norepinephrine. 5-HT and norepinephrine are projected downward to the spinal cord via the descending tract, which is involved in pain regulation.^{39,40} A new finding was that the sensory regulatory cortex in the brain directly projects to the spinal cord and participates in the enhancement of pain information in the spinal cord.⁴¹ Consequently, negative emotions of patients will be alleviated through narration, thereby reducing the subjective pain feeling

of patients. Patients with less pain will feel less depressed. Regarding inflammatory factors, after medication, the level of proinflammatory factors of the patients decreased, and this decrease in proinflammatory factors was more significant in patients who received the combined intervention. In previous studies, the effects of sleep on inflammatory factors have been confirmed.^{42,43} Depression affects inflammatory factors because the HPA axis stimulates the adrenal gland and secretes cortisol under stress. Cortisol stimulates immune cells to produce more proinflammatory factors, and proinflammatory factors can directly stimulate the brain, thereby bringing about emotional disorders, and create a vicious circle.⁴⁴

The Active Effect Of Online Patient Mutual Assistance Group On Patients

This study confirmed the positive role of an online patient mutual assistance group. People attribute to social activities and need to get a sense of identity, belonging and mutual support in the social network. Patients and their families can help each other, rebuild self-confidence and interpersonal relationships, and enhance social capital and social support through participating groups. This helps to improve their mental health. In addition, in the organization, professional medical personnel provide real-time health education and answer questions, which can be deemed a continuation of medical treatment and care. Under the guidance of professionals, patients achieved a higher treatment compliance and self-management level. A healthy lifestyle helps to alleviate the illness, and affects physiological indicators, such as inflammatory factors and mental health.

As a result, a positive impact of health education based on narrative medicine and online patient mutual assistance groups on patients was confirmed. Thus, in theory, when the two models were combined, the beneficial effect was increased. Through empirical research, the combination of the two positive health education methods was proven to be more conducive to the physical and mental health of patients when compared with a single model.

Limitations

However, this study has several limitations. First, there are many factors that affect patients' physical and mental health, including disease progression, individual constitution, sport, diet, and other factors. In the present study, we incorporated limited factors. Second, in the selection of the subjects, the sample size was small because the incidence of IBDA was low. Third, because interventions were carried out by different doctors, it was impossible to achieve the exact same

intervention for each patient. Therefore, in the future, narrative medicine will be systematically studied as a behavioral intervention model. More standardized clinical interventional pathways will be developed and employed. Moreover, more patients with chronic diseases will need to be included to carry out effect evaluation.

Conclusion

The empirical research conducted in this study confirmed that health education based on narrative medicine combined with an online patient mutual assistance group improved the health of IBDA patients. Therefore, this model needs to be further improved and promoted. Medical staff should enhance their narrative and empathic abilities, and actively promote the establishment and activities of patient mutual assistance groups.

Ethics Approval

This study was approved by the Wuhan University School of Medicine Ethics Committee (No. 20161101). This study was conducted in accordance with the Declaration of Helsinki. All patients signed an informed consent prior to participating in the study.

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Disclosure

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