Patients' perspectives on irritable bowel syndrome: a qualitative analysis based on social media in China

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Abstract

Aim To explore the perspectives, experience, and concerns of patients with irritable bowel syndrome (IBS) in China.
Methods We used data mining to investigate posts shared in Baidu Tieba concerned with IBS; we collected the data through the crawler code, and mined the cleaned data's themes based on Latent Dirichlet allocation (LDA) and the Grounded theory.
Results We found 5746 network posts related to IBS. LDA analysis generated 20 topics, and grounded theory analysis established eight topics. Combining the two methods, we finally arranged the topics according to five concepts: difficulty in obtaining disease information; serious psychosocial problems; dissatisfied with the treatment; lack of social support; and low quality of life.
Conclusion Social media research improved patient-centric understanding of patients' experiences and perceptions. Our study may facilitate doctor-patient communication and assist in the formulation of medical policies.

Keywords Irritable bowel syndrome · Latent Dirichlet allocation · Grounded theory · Social media

Introduction

Irritable bowel syndrome (IBS) is a prevalent functional gastrointestinal disorder characterized by chronic abdominal pain and altered bowel habits [1].The prevalence of IBS within the community is between 10 and 25% [2–4]. Meta-analysis shows global IBS prevalence at 11.2% [5]. The prevalence of IBS among Asian communities appears to be on the rise, especially in China [6]. Our previous survey of medical and engineering students in Zhejiang Province,

China founded that among 1870 participants, based on Rome III criteria, 129 were diagnosed as having IBS—an overall incidence of 6.90% [7].

The pathophysiology of IBS is incompletely understood [8]. Its diagnosis is based on symptoms. Therefore, despite the high prevalence, there is a lack of established therapeutic options. IBS has a substantial impact on people's health and well-being; hence it has with considerable socioeconomic consequences [9]. A study conducted in the US showed that IBS affects 10–15% of adults in that country, and is associated with significant impairment in health-related quality of life (HRQoL) [10]. Another survey, from Singapore, indicated that IBS sufferers were significantly affected in mobility, anxiety and depression, usual activity and pain [11]. There was a significant correlation between symptom intensity of IBS and deterioration of quality life (emotional health, mental health, energy, physical function, physical role, social role) [12, 13]. Society and culture may influence the expression and interpretation of IBS [14, 15]. A study on cross-cultural differences concerning IBS compared patients' intestinal symptom scale scores in eight countries, and the results showed significant differences in scores among countries, with Chinese patients ranking first and second in diarrhea and pain scores, respectively [16]. Recently, a team at Rome Foundation proposed that

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future studies of IBS should focus on regional and cross-cultural differences that are more likely to shed light on pathophysiology [17, 18]. It is particularly important to pay attention to patients with IBS according to different cultural backgrounds because it may reveal heterogeneity among nations concerning IBS research and management.

Chinese culture is strongly influenced by Confucianism and shows intrinsic sociocultural values which differ greatly from Western cultures. Previous studies from the perspective of patients with IBS, highlighted participants' frustration [19], social isolation [9], and dissatisfaction with medical care [20]. A survey in the US indicated that 68% of IBS patients would tell their partners about their condition, and 56% would tell other family members [9]. Another American survey found that IBS patients used more than 218 different medical methods to reduce symptoms, including prescription drugs, over-the-counter drugs, herbal medicine and diet therapy, but many were still dissatisfied with the treatments [20]. Besides, patients often have insufficient knowledge of IBS, thinking for example, that IBS may cause cancer [21]. Additionally, several studies have found that patients and doctors are often inconsistent in their understanding of etiology and judgments of severity, treatment and efficacy [20–22]. However, similar studies from China are lacking. Thus, there is a growing need to understand the experience of IBS patients in Chinese culture and their perspectives on factors contributing to the condition's severity.

Patients have gradually come to rely on the internet. An increasing number of patients, search online for relevant information before seeing a doctor, or they obtain medical services through the internet [23]. A study in the US found that 59% of users search for health information on the internet [24]. Social media play an especially important role for many people, including adolescents [25], pregnant women [26], and college students [27]. This is especially true since the onset of COVID-19 pandemic [28]. Social media allows researchers to better understand patients, especially among China's 800 million internet users. For this study, we collected IBS-related posts from Chinese social media and explored patients' experiences, perceptions, needs, and difficulties to patients to provide a panoramic view, based on the perspective of social media, of their feelings concerning IBS.

Materials and methods

Study design

Baidu Tieba (https://tieba.baidu.com) is the largest Chinese online community; like Reddit, it consists of a variety of subcommunities addressing topics and gathers massive user groups with different interests. IBS-Bar is a sub-bar

of Baidu Tieba and forms a community for IBS patients to communicate and discuss. As of May 20, 2022, the IBS-Bar had more than 10,000 followers and more than 150,000 posts and replies. The massive amount of user data generated in this open community is of great significance for analyzing IBS patients' experiences and perceptions. In this study, we mined posts from across the IBS-Bar's history (12 years). After data cleaning, latent Dirichlet allocation (LDA) topic modeling and grounded theory were used to explore the themes and understand the experiences and perceptions of IBS patients based on the perspective of social media. The workflow is presented in Fig. 1.

Our study team was made up of clinicians and nursing staffs. Three members (SS, JC, and LC) had received qualitative analysis training, and two members (HL and YJ) had experience in data mining; BL was a clinical expert concerning IBS. Trustworthiness of the data was established through triangulation and peer checking. Research triangulation was used to verify the accuracy of the coding process. In peer checking, two gastroenterologists assessed and confirmed the congruence between the raw data and the
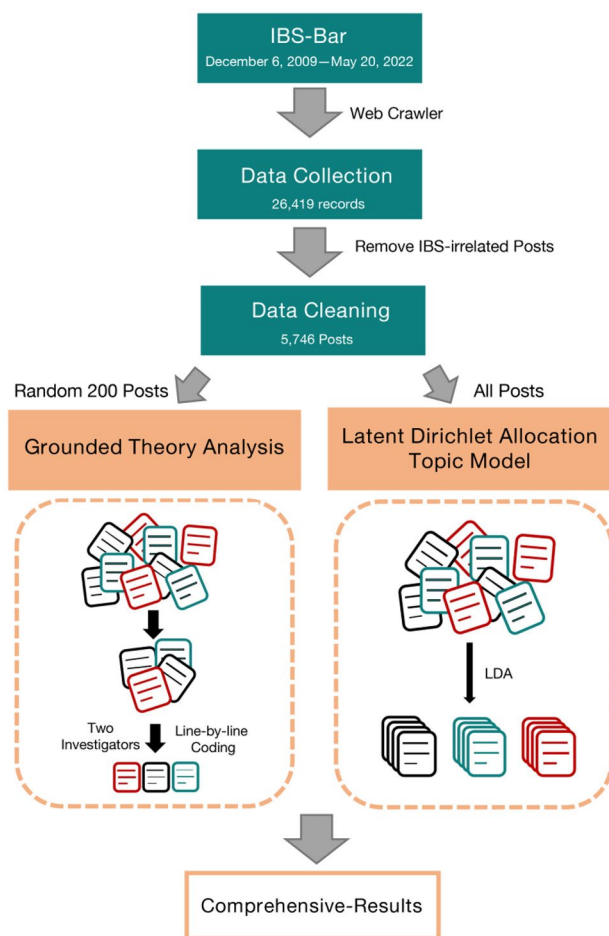

Fig. 1 Flow chart of the study

generated code and categories. The Standards for Reporting Qualitative Research (SRQR) [29] has been followed, and the checklist was completed (see Supplemental File 1: SRQR checklist).

Data collection and cleaning

All user posts (including comments and replies to posts) were written in Chinese and published online between December 6, 2009, and May 20, 2022.

By using the 'request' and 'selenium' packages and fast web crawling based on Python, we extracted the required data from web pages. A total of 26,419 records were collected. Subsequently, each post, with corresponding comments and replies, was combined into a single document for further analysis.

To assure the quality of the data, we removed blank lines, duplicate text, special symbols, numbers, and letters from the text, further eliminating texts with string lengths of less than 10, and retaining only Chinese strings. Additionally, we manually reviewed all posts and excluded advertised posts and posts unrelated to IBS. Finally, a total of 5746 posts were used for further analysis.

LDA topic model

According to Blei et al. [30], LDA is a probability-based topic model algorithm. It assumes that documents are generated based on a certain number of topics and that a given number of topics can be extracted from a corpus containing a certain number of documents [31]. In this study, we used 5746 posts as documents for further analysis. Each post was treated as a document.

In this study, a useful Python kit call 'Jieba' was first adopted to segment the Chinese sentences into separate terms. The second step was the deletion of stop words whose meanings could not be recognized from the word segmentation. Finally, we combined synonyms and phrases. Coherence scores were taken into consideration to determine the number of topics. Topic coherence is the most effective method of measuring the quality of topics; higher scores represent the most appropriate number of model topics [32]. After the optimal number of topics was determined, an LDA model was implemented using Gensim [33], a package that includes LDA. According to Gensim, "alpha" and "eta" are hyperparameters that affect sparsity of the topics and both defaults to 1.0/num_topics prior. Another Python package, 'pyLDAvis', was adopted to visualize the topic extraction results.

Finally, we went through representative clusters of terms and examined the most representative posts to define the topics.

Grounded theory

Once the posts were identified, we randomly selected 200 posts and used the grounded theory methods for analysis, as described by Charmaz [34]. This number was chosen based on the work experience of Gonzalez et al. [24], to achieve thematic saturation, meaning the point at which themes begin to be repeated.

Grounded theory is an iterative, hypothesis-generating approach that emphasizes the generalization or emergence of information from data to establish a theory or model [35, 36].Content analysis of data involved three stages: open coding, creating categories, and abstracting [37]. In the first stage, two investigators individually coded line-by-line to identify prominent issues and concepts. Then, we reviewed the codes and incorporated them into coding categories, which are groups of similar concepts and themes. Lastly, abstraction of sub-categories and generic categories was conducted in discussion among all authors, resulting in main categories that provided an overall description of patients' perspectives. Data analysis was completed using NVivo12 Plus software [38].

Mixed methods

The analysis of big data text based on grounded theory and LDA topic modeling has been recognized by many researchers [39–41], and the consistency of its results has also been verified. LDA helped us to synthesize a large amount of data, while grounded theory enabled us to verify identified themes and to more closely analyze the data. In this study, two researchers trained in qualitative techniques conducted analyses, comparing, contrasting, and combining topics from LDA, with themes from grounded theory to confirm similarities and differences. The final results were confirmed by the team's IBS clinical experts.

Ethics

All datasets were taken from Baidu Tieba, a publicly available website. Ethical approval was not required for the secondary analysis of publicly available data.
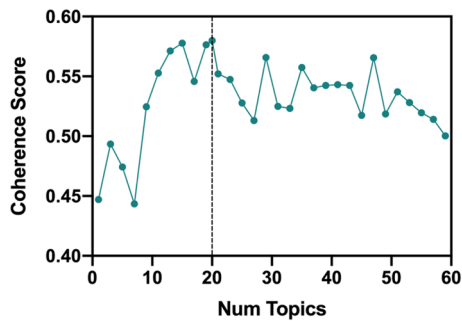
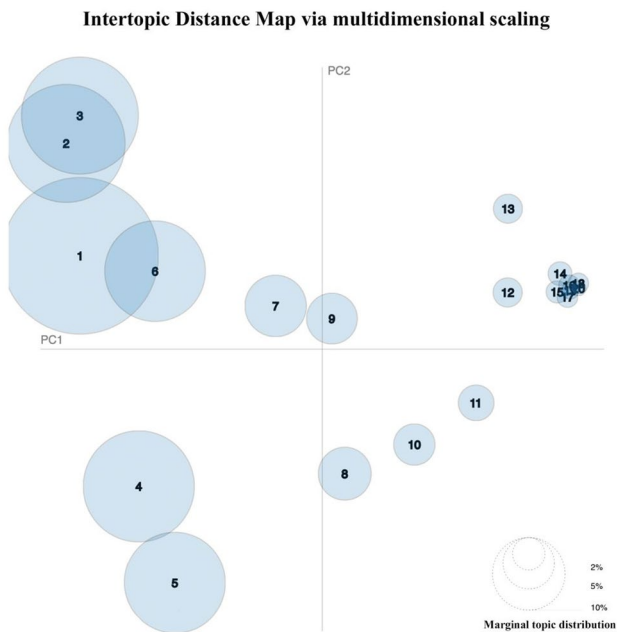**Fig. 2** Coherence scores for different numbers of topics

Fig. 3 Intertopic distance map

Results

LDA topic model analysis

We studied 5746 high-quality posts from Chinese social media that focused on IBS. Due to the restrictions concerning user privacy and internet information protection policies, there was no demographic information related to the data. Building on previous research that found 10–30 topics [42–44], but also considering smaller and larger topic numbers, consistency scores were calculated from 1 to 60 topics to obtain the optimal number of topics (Fig. 2). While $K = 16$, 17, and 19 also show high scores for coherence, we tend to choose a larger K value in order to ensure the breadth and depth of posts. This was confirmed after comprehensive consideration and thus a total of 20 topics were identified

(Fig. 3). More details and reasons for model selection can be founded in Supplementary file 2.

Table 1 shows the representative term cluster with each term's prevalence and assigned topic. The most common topic of the posts focused on discussions surrounding diagnosis and symptoms (mean share within posts = 24.2%), followed by topics on examination (13.7%) and diagnosis (13.5%). Discussions on mechanisms were also found as a separate but rather low-prevalence topic (1.7%). We also found one topic on emotional problems, the fourth most prevalent in the corpus (12.2%). Another two topics featured expressions of concern about drugs (10.1%) and complaints about life (10%). Four low-prevalence topics paid attention to medication experience (3.7%), alert symptoms (2.5%), Traditional Chinese medicine (TCM) (2.8%), and probiotics (1.3%). The remaining topics with low prevalence were distributed in peer support (0.8%), diet (0.8%), sport (0.6%), women (0.5%), nutrition (0.3%), social impact (0.4%), expert support (0.4%), study and work (0.4%), and nutrition (0.3%).

Grounded theory

During data analysis using grounded theory, we identified eight preliminary themes related to IBS patients' experiences and perception (Fig. 4): (i) Seeking disease information, (ii) Drug resistant/ drug ineffective, (iii) Lack of Home help, (iv) Avoiding social events, (v) Stigma in Women with IBS, (vi) Traditional Chinese Medicine, (vii) Seeking professional IBS hospitals/doctors, and (viii) Desire to improve quality of life.

Most of the topics encoded using grounded theory had been established in LDA topic modeling. However, grounded theory allowed us to be more explicit about patient attitudes, concerns, and perspectives. Besides, an additional important topic was found in our coding analysis: stigma in women with IBS. (e.g., "I don't want my family to know about my illness. I feel a little embarrassed").

Table 2 showed the process from codes to categorization using grounded theory. Coding tree presented complete main, generic, and sub-categories derived through the inductive content analysis process (Supplementary Fig. 1).

Results of mixed methods

Themes were generated using LDA and compared to the themes identified in the grounded theory analysis. We identified five themes with several subthemes, all of which are summarized in Fig. 4.

The most common theme (mean share within posts = 51.4%) were focused on seeking disease information,

Table 1 Representative term cluster with prevalence and assigned topic

Representative term cluster	Prevalence (%)	Topic
IBS, diarrhea, abdominal pain, symptoms, weight, constipation, chronic, toilet, tingling, prickling, halitosis, alternate, navel	24.2	Symptoms
Examination, enteroscope, stool, small bowel, blood routine, calprotectin, ulcer, uric acid, gastroscope, empyema, gastrointestinal tract	13.7	Examination
Diagnosis, confirmed, endoscopic report, criteria	13.5	Diagnosis
Spirit, mood, nervous, stress, anxiety, psychological, pain, depression, tired, discouraged, fear, adversity, shame, burden	12.2	Emotional problems
Take pills, cure, solve, loperamide, lansoprazole, laxative, sleeping pill, ineffective, resistant, gradually, wrong, invalid, futile	10.1	Drug resistant
Life quality, sleep, morning, catch cold, night, after meal, air-conditioning, attention, restricted diet, hobby, entertainment	10	Individuals' lives
Experience, medicine, effective, side effect, course, curative effect, useless, valid, standard, health products, Flupentixol and Melitracen Tablets, prebiotics,	3.7	Medication experience
Traditional Chinese Medicine, chines herbology, Recuperate, Lycium barbarum L, citri reticulatae pericarpium, dried ginger, Chinese jujube, plantago, saponism, ginger	2.8	Traditional Chinese medicine
Recrudescence, polyp, tumor, bleed, occult blood, organic, functional, angiography, positive signs, bacteria, colitis, allergy, hemorrhoids	2.5	Alarming symptoms
Inhibitory effect, Mechanism, Mast cell, inflammation, release, immune system, visceral sensitivity, sensitive,	1.7	Mechanism
Fecal Microbiota Transplantation, indication, effect, fecal bank, eradicate, donate, clinical experiment	1.3	Probiotics
Fellow sufferer, advice, give up, backer, share, method, healthy, communicate, Wechat group, hope, post	0.8	Peer support
Diet, fruit, milk, yoghurt, egg, flour, dinner, drink, tea with milk, bland diet, breakfast, lunch, vegetables, seafood	0.8	Diet
Sport, sweat, running, basketball, aerobic exercise, swimming, fitness, heart, walk, bike	0.6	Sport
Pregnancy, human milk, lactation, women, hereditary, menstruation, family, child, mother, sexual intercourse, gender	0.5	Women
Social contact, humble abode, inferiority, trouble, estranged, discrimination, stigma, friend, awkward	0.4	Social impact
Expert, doctor, hospital, Beijing, Shanghai, outpatient service, Peking Union Medical College, consult, hospitalization, recommend, third-class hospitals, popularization of science	0.4	Expert Support
Work, study, friend, go to school, work, colleague, occupation, dormitory, ridicule, community, night shift, stay up to late	0.4	Study and Work
Nutrition, dystrophy, weight, wasting, hunger, appetite, vitamin, protein, smoke, alcohol	0.3	Nutrition
Culture, season, reimbursement, country, resistance, progress	0.2	Others

followed by psychosocial problems (23.5%), such as difficulties in studying and working, lack of support at home, impaired social relations, and emotional problems. Besides, some populations, such as women, were particularly worried about pregnancy, genetics, and other issues. Treatment-related challenges were another serious problems (14.2%). Chinese IBS patients were disappointed with drug resistance but had high hopes for TCM and microbiota treatment. The remaining two low-prevalence themes focused on quality of life (6%) and lack of support (4.9%).

Discussion

A patient's perception of disease and medical treatment is at the core of medical practice [45]. Patients' emotions and life challenges are often more important than the physical discomfort caused by the IBS [19].There has been increased scientific attention to understand the nature of medical disorders from the patient's perspectives. Patients with IBS often experience symptoms for many years, with an average duration of 10 years or more [46]. There has been an underestimation of the impact of IBS on an individual's functioning and quality of life (QoL) [47]. When IBS patients show up at outpatient clinics, physicians intuitively assess symptoms' severity to plan diagnostic evaluation and treatment recommendations [48], however,
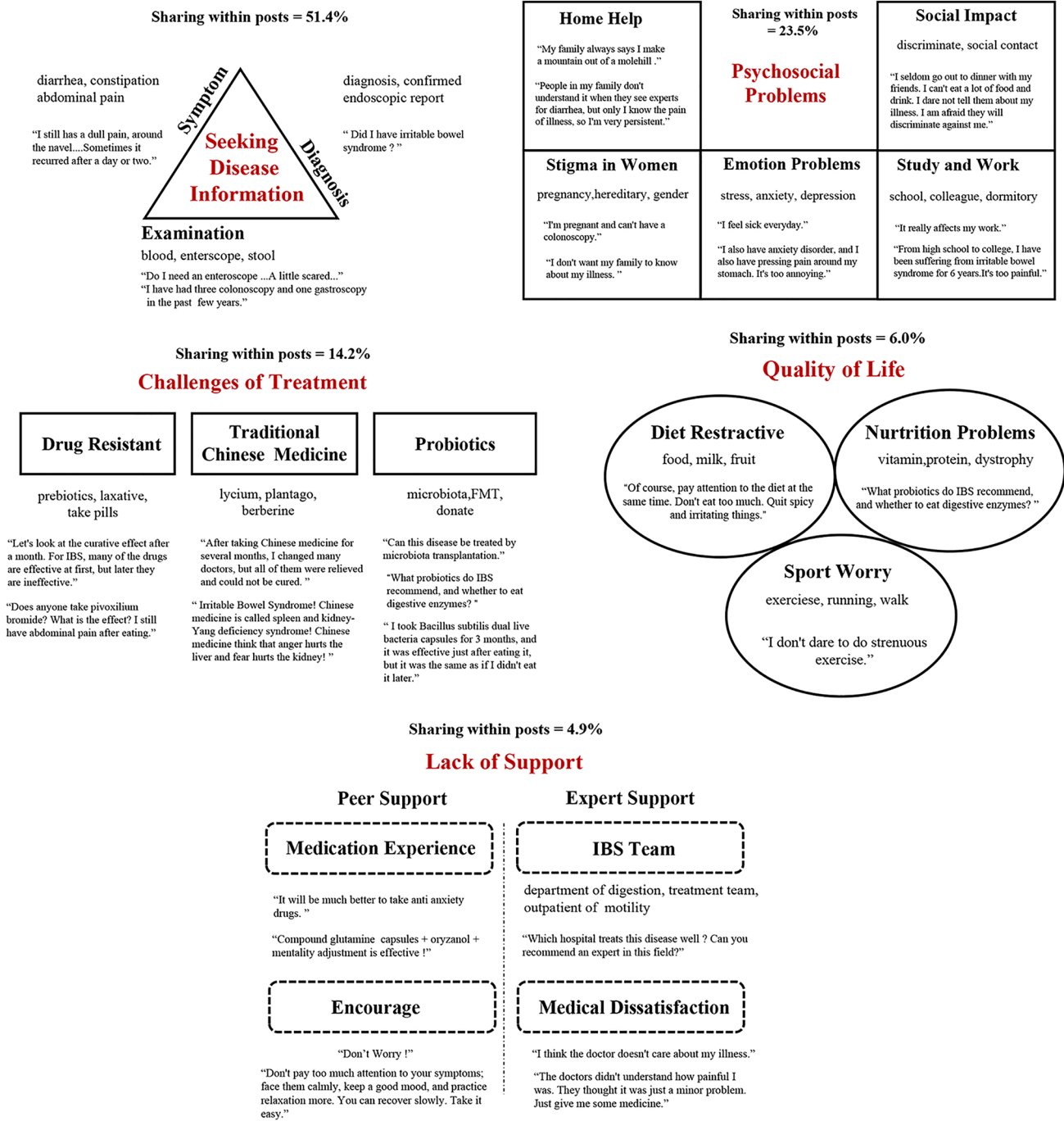
Fig. 4 Themes identified using mixed methods

evidence suggests that physician-determined prevalence of moderate and severe IBS has been underestimated [49, 50]. Thus, severity of IBS must be based on the patient's experience. Currently, little is known concerning how to define or understand, from the patient's perspective, factors contributing to severity. Our research summarized posts on IBS-Bar over 12 years, and we conducted a comprehensive analysis in order to fully understand the patients' perspective, experience, and concerns.

Patients always seek information related to a specific illnesses or disease [51]. In our study, seeking disease information is a major concern, when it comes to IBS. IBS, as one kind of functional bowel disorder, contains four subtypes [52]. In our study, the two main symptoms that troubled patients were abdominal pain and diarrhea. The

Table 2 Examples of coding processes using grounded theory

Meaningful unit	Code	Sub-category	Generic category	Main category
'I still has a dull pain, around the navel… Sometimes it recurred after a day or two.'	Abdominal pain	Symptom of IBS	Asking about the symptoms and diagnosis	(i) Seeking disease information
'I need to flush into the toilet every morning, and repeat it many times.'	Diarrhea			
'I have done many enteroscopy examination because of abdominal pain.'	Enteroscopy	Diagnosis of IBS		
'I went to the hospital for abdominal pain and performed an abdominal CT scan.'	Abdominal CT			
'My family never thought it was a problem.'	Overlook of family	Family ignored needs	Attitude of families	(v) Lack of home help
'My parents think this is common gastrointestinal symptoms.'				

results were consistent with previous studies. These people posting these descriptions wanted to know if they could be diagnosed with IBS. A survey of 29 international experts showed that 53% believed bloating was the most important feature of IBS patients; abdominal pain was agreed by only 25% of the experts [53]. The Rome IV diagnostic criteria only lists abdominal pain as the main symptom of IBS [54], but Chinese experts believe that both abdominal distension and abdominal discomfort should be included in the definition of IBS [55]. It is therefore more likely that a problem of overdiagnosis leads to unnecessary, repeated medical treatment and psychological effects. Besides, we found some posters thought they had IBS, although they hadn't been to the hospital for a diagnosis. Worldwide, 30–70% of patients with IBS visit a doctors, with an overall visit rate of 40% [56]; however, the rate is only 22% in China [57]. Thus, China's IBS patients may tend to self-diagnose rather than seek medical diagnoses. This could possibly introduce treatment error because self-medication is strongly related to self-diagnosis [58].

In our study, psychosocial problems marked the second-largest group of themes mentioned by Chinese patients with IBS. In a US population-based survey, IBS led to a mean of 0.8 missed days and 4.9 days' disrupted productivity per month [59]. Another American study showed that in addition to significantly interfering with normal work, IBS caused people to miss out on leisure and on social interaction [19]. In addition, some posters felt that family members did not fully understand their distress. This indicates that Chinese patients with IBS cannot get good help at home. This finding differs from previous studies [9]. We speculate that it may be related to cultural background, because Chinese families may lack suitable atmosphere for direct emotional expression [60]. Various kinds of help or assistance from family, friends, and others were described as social support. In our study, emotional problems were another major category of problems patients had with self-expression.

Some individuals reported distress, anxious and depression, even thoughts about death. According to evidence, disordered gut-brain interaction is one of the causes of IBS [61]. Depression, anxiety, and somatoform disorders are the most common psychiatric diagnoses in IBS [62]. Several previous studies from China have shown that patients with IBS are associated with psychosomatic abnormalities, and neuromodulators can improve gastrointestinal symptom [63, 64]. It is worth noting that some groups, such as women tended to experience greater with IBS. Some female patients often expressed a sense of stigma in their posts. It made them feel embarrassed to tell anyone about their symptoms, even their husbands or family members. A study by Toner et al. found that bowel functioning becomes a source of shame and embarrassment for more women compared to man [65]. In a sex-related study of IBS, Björkman and colleagues concluded that women and men experience IBS differently because of their different roles in society [66]. Besides, some women, especially pregnant if they are pregnant, worry that IBS may be passed on to their children. Some pregnant women do not dare to take any medicine for fear of affecting their children.

Treatment of IBS remains a challenge [67]. Many patients approve drugs' efficacy on their initial use, but after an initial period, drugs lose their effects. This leads patients to switch medicines repeatedly and keep seeking other treatments. A survey in the United States found that patients with IBS were treated using 281 different medical methods; less than a third of the patients were satisfied with the effects, and two fifths expressed very dissatisfaction [20]. Frequent changes of doctors and discontinuations of treatment are also quite common for patients with IBS [68]. Current therapies based on adjusting the gut microbiome mainly include probiotics and fecal transplantation. Our study shows that Chinese patients with IBS have high hopes for both. Recent studies suggest a role for such alterations in gut microbiota [69, 70]. Multiple meta-analyses have

provided evidence for the beneficial effects of probiotics in IBS treatment, including mitigation of abdominal pain, bloating, and overall symptom scores [71]. However, not all probiotics exhibit beneficial effects, and it is not clear which probiotics are the most beneficial. Similarly, a study of Fecal Microbiota Transplantation (FMT) in patients with moderate-to-severe IBS-D or IBS M showed that 3 months after transplantation, IBS symptoms were significantly improved in the FMT group compared with the placebo group. The remission rate was significantly higher in the FMT group than in the placebo group (65% vs. 43%) [72]. Since then, numerous other studies have been carried out, but in a recent meta-analysis, it was shown that FMT did not significantly alleviate patients' clinical symptoms of IBS, and the results were highly heterogeneous [73]. While probiotics and FMT treatment are still in the early stages of research, their specific efficacy is still being repeatedly verified.

Peer support provides a unique perspective of shared experience that can instill hope and assist other patients [74, 75]. Although many posts referenced experience of treatment and encouraged others to seek treatment, many patients still hoped for more experience of medication, side effect, efficacy, and so forth. However, peer support may disseminate inaccurate information. Numerous studies have shown that peer-support providers find the transition from "patients" to "provider" challenging [76, 77], suggesting that providers of peer support may need training before they can play their new role well. The severity of IBS cannot be determined objectively because symptoms are subjective [19]; thus, expert support based on rich experience, is necessary. In our study, some individuals complained about their terrible experience during medical visits. They felt that their condition was not fully understood or taken seriously by doctors. A similar situation has appeared in other studies [78]. In addition, some posts revealed there are people who don't think they are getting professional treatment. This indicates a need for more professional functional gastroenterologists to meet patients' needs in China.

IBS can have a substantial effect on a person's quality of life. Studies have shown that the patients' quality of life is significantly lower with IBS than with organic diseases, such as diabetes and gastroesophageal reflux disease [10]. Our study found that diet, sport, and nutrition were serious concerns for patients with IBS. Some posts suggested that the doctors can't give specific dietary advice; patients can only grope and record observations by themselves. This also makes them worry about their own nutritional problems. Diet plays an important role not only in the treatment of IBS, but also as a tool that improves symptoms and quality of life [79]. Recent studies show that low-FODMAP diet alleviated bloating, flatulence, diarrhea, and global symptoms in 50%-80% of patients with IBS [80]. Some patients believe that

IBS prevents them from exercising vigorously. In fact, increased physical activity improves GI symptoms in patients with IBS [81, 82] and may be used as a primary modality for treatment of IBS [83]. The evidence indicates that Chinese patients with IBS still risk making cognitive errors and need more health education.

This study combined grounded theory with LDA topic modeling, the former a qualitative approach and from interpretive social science [84] and the latter a quantitative approach from natural language processing. This allowed us to process massive quantities of data and to maintain the linguistic, contextual, and interpretive insight that can only come from human reading [39]. Compared to a solely quantitative analysis, a qualitative approach can realize deep insights from textual data. Although qualitative research requires more manpower and time, it is worthwhile because it enables us to find topics that may be ignored during the LDA analysis. In addition, we were able to compare themes derived using each method to ensure consistency in capturing the breadth and depth of online discussions.

There remain limitations concerning this study. Some of the posts included in the analysis may have been made by people with gastrointestinal symptoms, which may not be due to IBS. Data quality would be improved if the posts could be identified by a machine learning classifier. Of course, this still needs further research. Moreover, Our study ignored patients with IBS, who were not users of social media. Further, Our study focused on Chinese patients, thus lacking comparative data on patients from other cultural backgrounds. It is worth noting that all the data in this study were based on the network. Compared with traditional interview methods, it remains unknown whether the methods adopted in this article reach the required data depth. Hopefully some of our peers will do more work in this regard. In addition, member checks were not completed as part of this study. Since this is based on data from social media sources, we would not have been able to get timely feedback from participants to correct our themes.

Conclusion

Patients' experience of IBS, and their perceptions of the condition, have important clinical and public health implications. To better understand these implications, our study turned to social media. The results shed light on the needs and difficulties of Chinese patients with IBS: difficulty in obtaining disease information; serious psychosocial problems; dissatisfaction with the treatment; lack of social support, and low quality of life. This study can help medical staff predict the thoughts and concerns that IBS patients may have during the treatment process, facilitate doctor-patient

communication, and assist in the formulation of medical policies.

Author contributions SS, and JC wrote the main manuscript text; SS and HL analyzed the data; YL and LC prepared the figures; BL designed this study and revised the article.

Data availability The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

Declarations

Competing interest The authors declare no competing interests.

Ethical approval All datasets were taken from Baidu Tieba, a publicly available website. Ethical approval was not required for the secondary analysis of publicly available data.

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