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Observational Study

Knowledge, attitude, and practice of patients living with inflammatory bowel disease: A cross-sectional study

Shao XX *et al.* KAP of IBD among patients

Abstract

BACKGROUND

Patients with inflammatory bowel diseases (IBDs) generally have poor knowledge, attitude, and practice of their disease, while the data from China are lacking.

AIM

To address this knowledge disparity among Chinese patients with IBD.

METHODS

This web-based, cross-sectional study was conducted on a cohort of IBD patients who visited the Second Affiliated Hospital of Wenzhou Medical University between December 2022 and February 2023. Their socio-demographic information and the knowledge, attitude, and practice scores were collected and estimated using a self-designed questionnaire. Pearson's correlation analysis was used to determine the pairwise correlations among knowledge, attitude, and practice scores. A multivariate logistic regression analysis was further performed to determine the independent factors associated with their knowledge, attitude, and practice scores.

RESULTS

A total of 353 patients (224 males) with IBD completed the questionnaires. The mean knowledge, attitude, and practice scores were 10.05 ± 3.46 (possible range: 0-14), 41.58 ± 5.23 (possible range: 0-56), 44.20 ± 7.39 (possible range: 0-56), respectively, indicating good knowledge, positive attitude, and proactive practice toward IBD. Pearson's correlation analysis showed that the knowledge score had significant positive correlations with the attitude score ($r = 0.371$, $P < 0.001$) and practice score ($r = 0.100$, $P < 0.001$). The attitude score had a significant positive correlation with the practice score ($r = 0.452$, $P < 0.001$). Moreover, multivariate logistic regression analysis showed that aged 30-40 years [odds ratio (OR) = 4.06, 95% confidence interval (CI): 1.04-15.82, $P = 0.043$], middle school education (OR = 3.98, 95%CI: 1.29-12.33, $P = 0.017$), high

school/technical secondary school education (OR = 14.06, 95%CI: 3.92-50.38, $P < 0.001$), and junior college/bachelor's degree and above education (OR = 15.20, 95%CI: 4.15-55.650, $P < 0.001$) were independently associated with good knowledge. The higher knowledge score was independently associated with a positive attitude (OR = 1.23, 95%CI: 1.11-1.36, $P < 0.001$). The higher attitude score was independently associated with proactive practice (OR = 1.20, 95%CI: 1.11-1.30, $P < 0.001$).

CONCLUSION

Chinese patients with IBD might have good knowledge, a positive attitude, and proactive practice toward their disease. However, a small number of specific items require education.

Key Words: Attitude; Cross-sectional study; Inflammatory bowel disease; Knowledge; Practice; Questionnaire

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Core Tip: To address this knowledge disparity among Chinese patients with inflammatory bowel disease (IBD), a web-based, cross-sectional study was conducted on 353 IBD patients (224 males). Their mean knowledge, attitude, and practice scores were 10.05 ± 3.46 (range: 0-14), 41.58 ± 5.23 (range: 0-56), and 44.20 ± 7.39 (range: 0-56), respectively. Multivariate logistic regression analysis showed that age and education were independently associated with knowledge. Knowledge was independently associated with attitude. The attitude was independently associated with the practice. In conclusion, patients with IBD in China might have good knowledge, a positive attitude, and proactive practice toward their disease. However, some specific items require education.

INTRODUCTION

² Inflammatory bowel disease (IBD) is a chronic, non-specific inflammation of the gastrointestinal tract, including ulcerative colitis and Crohn's disease. The IBD usually develops before age 30^[1-3]. Moreover, IBD is associated with a poor quality of life and may increase colorectal cancer risk^[2-4]. The individual management strategy of IBD is tailored to each patient according to diagnosis, disease activity grade, disease lesion, and personal prognostic factors^[1,3-7]. Despite this, IBD continues to be difficult to manage, as treatment adverse effects and repeated exacerbation/recurrence episodes can eventually necessitate costly second-line therapies or even surgery^[8-11].

Maintaining proper lifestyle habits is necessary and complementary to medical treatments in patients with IBD^[12,13]. Fundamental to patient self-management is knowing which foods and situations to avoid and what can be done to alleviate symptoms^[12,13]. To implement adequate self-management, a thorough understanding of IBD causes, risk factors for exacerbation/recurrence, disease mechanisms, and treatments is essential, and this knowledge needs to be translated into more effective (but not infallible) self-management. In addition, since there is no cure for IBD, self-management is essential to its treatment^[1,5,14]. Indeed, since the management of IBD necessitates the adoption of healthy lifestyle habits, IBD patients are the first to be accountable for their health^[12,13], which requires proper knowledge, attitudes, and practice (KAP) of the specific lifestyle routines to implement. The appropriate KAP about IBD can reduce medical acceleration in patients with IBD^[15]. Since the 1990s, however, some studies have revealed that patients with IBD have misconceptions and limited knowledge of their disease^[16-21]. Such studies are important to identify the gaps in knowledge that represent barriers to the proper management of IBD. Identifying these obstacles could also aid in designing interventions to enhance or rectify knowledge^[22,23]. Owing to significant differences in culture, economy, health literacy, healthcare systems, and government policies, KAP data are usually very specific to a

given population. Of note, data about the KAP toward IBD in Chinese patients with IBD are lacking.

The KAP methodology provides quantitative and qualitative data on the misconceptions that could represent obstacles to a specific task/subject in a specific population^[22,23]. Hence, this study aimed to investigate the KAP of patients with IBD toward their disease in Zhejiang Province, China. The results could help healthcare providers to improve the patient's self-management of IBD.

MATERIALS AND METHODS

Study design and participants

It was a cross-sectional study conducted on patients with IBD at the Second Affiliated Hospital of Wenzhou Medical University using convenience sampling. Our study was approved by the ethics committee of the same hospital (approval No. 2022-K-184-02). Each patient provided written informed consent before completing the survey.

Procedures

The questionnaire was designed with reference to the World Gastroenterology Organization Practice Guidelines for the Diagnosis and Management of IBD in 2010^[24] and the clinical nutrition guideline for IBD by the European Society for Clinical Nutrition and Metabolism in 2016^[25]. Then, the questionnaire was submitted to 5 experts for review. After the modifications based on their comments, a small-scale validation was performed (33 copies), showing a Cronbach's α of 0.854.

The final questionnaire was in Chinese patients with IBD and included four dimensions with 62 items. Among them, the socio-demographic information dimension consisted of 20 items. The knowledge, attitude, and practice dimensions consisted of 14 items each. The items in the knowledge dimension were scored 1 point for a correct answer and 0 points for a wrong or unclear answer (total score of 0-14). The options from positive to negative (*e.g.*, 4 to 0) were assigned for the attitude and practice dimension. The total scores were 0-56 for the attitude dimension and 0-56 for the

practice dimension. The threshold for good knowledge, positive attitude, and proactive practice was $\geq 70.0\%$.

The questionnaires were administered to the participants through WeChat on the SoJump platform (<https://www.wjx.cn/app/survey.aspx>). A given IP address could be used to submit a questionnaire only once. All items must be answered before the submission of the questionnaire. Questionnaires that took less than 2 min to complete or with obvious filling patterns were excluded.

Statistics analysis

All analyses were performed using Stata 17.0 (Stata Corporation, College Station, TX, United States). The normal distribution of continuous data was checked using the Kolmogorov-Smirnov test. Those continuous data conforming to the normal distribution were presented as means \pm SD and analyzed using Student's *t*-test (two groups) or ANOVA (more than two groups). Otherwise, they were presented as medians (ranges) and analyzed using the Wilcoxon-Mann-Whitney *U*-test (two groups) or the Kruskal-Wallis analysis of variance (more than two groups). Categorical data were displayed as numbers (percent). Pearson's correlation analysis was used to determine the pairwise correlations among KAP scores. A multivariate logistic regression analysis was performed to determine the independent factors relevant to the KAP score. Variables with *P*-values less than 0.20 in the univariate analysis were included in the multivariate logistic analysis. Two-sided *P*-values below 0.05 were regarded as statistically significant.

RESULTS

The present study included a total of 353 valid questionnaires. Most of the participants were male (63.5%), aged 20-30 (32.9%) years. The other social-demographic data are presented in Table 1. The mean knowledge, attitude, and practice scores were 10.05 ± 3.46 (possible range: 0-14), 41.58 ± 5.23 (possible range: 0-56), and 44.20 ± 7.39 (possible

range: 0-56), respectively, indicating good knowledge, positive attitude, and proactive practice toward IBD (Table 1).

The knowledge items with the lowest score were K2 (21.0%, "At present, and many factors such as heredity, immunity, environment, and microorganisms are involved in the pathogenesis of the disease"), K11 (42.2%, "There are no side effects under the therapy of glucocorticoids, *etc.*"), K4 (60.1%, "Extraintestinal manifestations of IBD include oral ulcers, joint injury, skin injury, eye lesions, hepatobiliary diseases, *etc.*"), and K13 (65.7%, "All patients with IBD cannot normally absorb the nutrients they intake") (Table 2). The attitude item with the lowest score was A8 ("I think that treatment can be stopped when the colonoscopy shows mucosal healing *i.e.*, complete healing of colonic erosions and ulcers") (Table 3). The practice item with the lowest score was P11 ("I will use a diet diary to identify foods that may cause discomforts such as abdominal pain or diarrhea and try to avoid them in my future diet"). In addition, 98.0% of the participants were willing to stop smoking and drinking (Table 4).

The knowledge score was found to be related to the attitude score ($r = 0.371$, $P < 0.001$) and practice ($r = 0.100$, $P < 0.001$) score, respectively. The attitude score was related to the practice score ($r = 0.452$, $P < 0.001$) (Table 5). Moreover, multivariate logistic regression analysis suggested that aged 30-40 years [odds ratio (OR) = 4.06, 95% confidence interval (CI): 1.04-15.82, $P = 0.043$], middle school education (OR = 3.98, 95%CI: 1.29-12.33, $P = 0.017$), high school/technical secondary school education (OR = 14.06, 95%CI: 3.92-50.38, $P < 0.001$), and junior college/bachelor's degree and above education (OR = 15.20, 95%CI: 4.15-55.650, $P < 0.001$) were independently linked with the knowledge score (Table 6). The knowledge score (OR = 1.23, 95%CI: 1.11-1.36, $P < 0.001$) was independently associated with the attitude score (Table 7). In addition, the attitude score (OR = 1.20, 95%CI: 1.11-1.30, $P < 0.001$) had an independent effect on the practice score (Table 8).

DISCUSSION

The findings of our study suggested that Chinese patients with IBD had good knowledge, positive attitudes, and proactive practice toward their disease. Nevertheless, some specific items warranting more education were identified. These outcomes may be useful for the management and self-management of IBD patients in clinical practice.

Several studies revealed misconceptions and relatively poor knowledge in patients with IBD about their disease^[16-21]. A study from England published 30 years ago already acknowledged that patients with IBD had poor knowledge regarding their disease but were willing to acquire information^[16]. More contemporary data indicated little progress since then, *i.e.*, that the knowledge of patients with IBD toward their disease was poor^[17-21], including in New Zealand^[17], Canada^[18], Israel^[19], Poland^[20], and South Korea^[21]. Surprisingly, in the present study, the patients with IBD showed good KAP toward IBD, but it could be noted that most participants had a junior college/bachelor's degree and above education and were receiving expensive biological agents, thereby suggesting a higher socioeconomic status that could influence the results.

The present investigation also demonstrated that age and educational attainment were independently associated with knowledge scores. Specific knowledge items that need improvement include the etiology of IBDs, the possible extraintestinal manifestations of IBDs, the side effects of glucocorticoids, and nutrient absorption. Even though the other knowledge items had high scores, none scored above 90%, indicating they would benefit from additional instruction. Furthermore, knowledge was the only factor independently associated with the attitude score, and attitude was the only factor independently connected with the practice score. Hence, improving the knowledge of patient about IBDs should enhance their KAP. Since a proper KAP of IBDs has been associated with better IBD outcomes^[15], improving the KAP can improve patient outcomes, given that self-management is at the core of IBD management^[12,13].

Still, patients obtain knowledge primarily from available resources (books, the internet, newspapers, *etc.*), their social network, and healthcare professionals. A study highlighted variable access to high-quality information on IBD-related nutrition^[26], and

nutrition is a major factor influencing the intestinal microflora and the outcomes of IBDs^[27-29]. Furthermore, a study in New Zealand showed that the KAP of IBD in the general population was also low^[30,31], suggesting that patient education is deficient or ineffective since the patients with IBD have poor KAP. Healthcare providers are the primary source of reliable patient information, but studies unveiled that the KAP of IBD among healthcare providers was also low^[32,33]. Having limited knowledge about a disease can impede the spread of accurate information. Therefore, previous studies suggest that priority should be placed on educating patients, healthcare professionals, and the general public.

There are some limitations in this study. It was conducted at a single institution, limiting its applicability to other hospitals in China. The questionnaire was designed by local investigators and was probably influenced by local policies and guidelines, further restricting the exportability of the questionnaire. The study has local scope, and the results cannot be extrapolated to other populations, which makes similar studies necessary in other locations. The study population shows high education and use of biological products, which suggests a selection bias. KAP surveys represent the situation of a specific population at a precise time point. Therefore, studies in other populations and time might be necessary to examine the actual KAP situation in China and the effect of education. Finally, all KAP surveys were susceptible to social desirability bias, in which participants may have been more likely to provide the expected response than the actual answer^[34].

CONCLUSION

In conclusion, this study suggests that Chinese patients with IBD have good knowledge, positive attitudes, and active practice toward their disease. Nevertheless, some specific items warranting more education were identified, especially regarding the etiology and contributing factors to the disease, extraintestinal manifestations, glucocorticoid side effects, and nutrient absorption.

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PRIMARY SOURCES

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