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ORIGINAL ARTICLE

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Knowledge of disease and health information needs of the patients with inflammatory bowel disease in a developing country

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Abstract *Background and aims:* This study was performed to have a first-time assessment on the knowledge level of a population of inflammatory bowel disease (IBD) patients in a developing country like Iran and to identify their health information preferences. *Methods:* One hundred over 18-year-old IBD patients presenting to an outpatient gastroenterology clinic in Tehran from April to November 2004 were asked to complete Persian-translated version of 24-item Crohn's and Colitis Knowledge (CCKNOW) score questionnaire and an additional questionnaire collecting their favorite disease-related knowledge topics. *Results:* All of the patients (64 females, 36 males) wished to know more about their disease. The cause of IBD and the medications were the most favorite knowledge topics. The mean and median of CCKNOW score of the patients was 4.65 and 4.0 (out of 24), respectively. Women showed significantly higher scores than men (p=0.006). There was also a weak positive correlation between the level of education and CCKNOW score (Spearman's ρ=0.23, p=0.02). No significant correlation was found between age, duration of disease, self-estimated level of suffering from disease, and CCKNOW score. The most severe knowledge deficit was evident in knowledge on IBD complications. *Conclusion:* Despite the overt inclination of Iranian IBD patients to know more about their disease, their knowledge levels were significantly lower than the IBD patients in developed countries. The more profound knowledge deficit in IBD complications may lead to disastrous aftermaths such as late diagnosis of colorectal cancer induced by prolonged IBD. Vigorous patient education programs for the Iranian IBD patient are suggested focusing on areas of knowledge deficit and their favorite topics.

Keywords Inflammatory bowel disease · Patient education · Knowledge assessment · CCKNOW

Introduction

Inflammatory bowel disease (IBD), which includes two major types, Crohn's disease (CD) and ulcerative colitis (UC), causes patients to suffer chronically from diarrhea, abdominal pain, gastrointestinal bleeding, malabsorption, and weight loss. Geographically, the prevalence of IBD has a slope from North to South and, to a lesser degree, from West to East. Although the studies on Asians in Asia showed relatively low incidence rates for UC and CD compared with North America and Europe, the incidence of disease is rising in these regions where IBD was less common [1–3].

The onset in early adult life, disease chronicity, the need for visiting physician, laboratory tests, diagnostic procedures, hospitalization, and surgery causes high economic costs for IBD patients and society in both UC and CD [4–6].

Although UC compared with CD has less profound effects on health-related quality of life (HRQOL), both have a significant impact on it [7]. Patients visit physicians frequently, having great concern about their disease, including both physical and psychosocial issues [8, 9]. On the other hand, IBD could cause patients to suffer from depression and anxiety more than general population [10].

Patients' knowledge and understanding varies widely in IBD. Some patients show evidence of advance reading about IBD and its treatment options. Others do not possess even a basic understanding of their condition and have virtually no recall of previous discussions with their physician. A working knowledge of their disease and its management is essential for patients with chronic disorders such as IBD [11]. Almost all IBD patients feel that information and knowledge on their disease according to their needs would be useful and helpful in IBD control, and most of them believe that adequate information would allow them to initiate a proper treatment before visiting their doctor [12, 13].

Although some studies show that patient knowledge has no effect on HRQOL [14–16], there is more evidence indicating that higher levels of knowledge about disease improve HRQOL in IBD patients [17–19]. Some IBD patients think knowledge of the possible severity of their disease might increase their anxiety [13]. However, several studies showed that education does not cause anxiety in IBD patient [16, 20]. Patients with higher knowledge of IBD have fewer concerns [19], better reaction to the disease [21], and better relationship with their physicians [17]. In addition, some studies evaluated self-management education in IBD patients and revealed that the patients educated for self-management had greater confidence in being able to cope with their disease. In these patients, self-management education decreased the number of physician visits, use of primary health care services, and hospital visits without causing more anxiety, morbidity, or impairment in HRQOL [22, 23].

To the authors' knowledge, there is scanty or at least no PubMed-indexed data on the level of knowledge and health information preferences of IBD patients from developing countries. This study was performed to have a first assessment on the disease-related knowledge level of a population of IBD patients in a developing country like Iran, detect knowledge deficit areas, and identify their health information preferences as a guideline for patient education activities for IBD patients in the country. In addition, the results of the study were to be used in a pilot Persian web-based patient education project dedicated to IBD patients.

Materials and methods

Consecutive IBD patients presenting to an outpatient gastroenterology clinic in Tehran from April 24 to November 10, 2004, were asked to fill a self-assessed questionnaire after their gastroenterology visit. The illiterate and under 18-year-old patients were not included. Before filling the questionnaires, an educated nurse explained to the patients about the purpose of the study and stressed that entering the study was voluntary and all patients' data would remain confidential.

The questionnaire included two parts. The first part collected demographic data, patients' propensity to know more about their disease, and favorite disease-related information. A question in this part also assessed the subjective perception of patients of the level of suffering from IBD in their everyday life on a 5-scale Likert. The second part of the questionnaire included the 24-item Crohn's and Colitis Knowledge (CCKNOW) score [11] translated into Persian. CCKNOW score is a valid index of high internal consistency and a good level of reliability that assesses disease-related knowledge of IBD patients in four knowledge areas regarding IBD management, including general understanding, treatment, diet, and complications. The questionnaire was chosen not only because of its high validity and reliability but also for its assessing different areas of knowledge and so detecting the areas of knowledge deficit. Scoring for CCKNOW is one point for each correct answer with no negative marking and the maximum possible score is 24 [11].

Since the developers of CCKNOW did not directly define the knowledge area each question assessed in the relevant publication [11], authors (MR and DR) assigned each question of the 24-item CCKNOW questionnaire to one of the four knowledge areas mentioned above.

The mean of CCKNOW scores of patients was calculated for CD and UC patients. To make a comparison of the four knowledge areas (see above), the mean of the ratio of patient's total score of each area to full scores of that area was calculated and expressed in percents for all patients. Since the data distribution of the patients' CCKNOW scores were not normal, the Spearman's ρ was used to assess the correlation between CCKNOW score and patients' age, duration of disease, level of education, and self-estimated level of suffering from disease. Mann–Whitney U test was used to compare CCKNOW scores between two genders. Chi-square test was used to detect any statistically significant relationship between patients' sex or college/university education and their favorite knowledge topic.

Results

One hundred IBD patients over 18 years of age (86 with UC, 9 with CD, and 5 with indeterminate IBD) agreed to fill the self-assessed questionnaire. The patients comprised 64 females and 36 males. The mean (SD) of patients' age was 36 (±10) years. The frequency of patients' age, sex,

education level, IBD type and duration, the self-estimated level of suffering from disease, and the corresponding mean CCKNOW score are shown in Table 1.

Most patients (86%) had UC. The median duration of disease was 4 years (range 0 to 28 years), and 75% of patients had IBD for less than 9 years. Since the number of the patients with CD was much lower than (almost one tenth of) those with UC, statistical analysis of data variables, such as CCKNOW scores, favorite knowledge topics, etc., were not performed by disease type.

All of the patients expressed that they wished to know more about their disease. Table 2 shows the favorite disease-related knowledge topics by patients' sex and type of IBD. The most favorite topics were cause of disease (89%) and drug complications (79%). Females were more inclined than males to know about medications used for IBD treatment (p=0.03) and the effect of IBD on fertility, pregnancy, and breast feeding (p=0.01). A higher predilection for knowing more about anatomy of gastrointestinal system (p=0.014) and medications (p=0.006) was found in the patients with university/college education.

The mean and median of the patients' CCKNOW scores were 4.65 and 4.0 (out of 24), respectively. While the maximum CCKNOW score among our patients was 16 (only one patient), 90% of the patients had a score below 9. Table 1 shows the mean CCKNOW score of patients by age, sex, type of disease, educational level, disease duration, and self-estimated level of suffering from disease. Women showed significantly higher scores than men (p= 0.006). There was also a weak positive correlation between the level of education and CCKNOW score (Spearman's ρ=0.23, p=0.02). However, no significant correlation was found between age, duration of disease, or self-estimated level of suffering from disease and CCKNOW score.

The proportion of patients who answered correctly to each question in the 24-item CCKNOW questionnaire is set out in Table 3. Table 4 shows the proportion of patients answering questions in each of the four disease-related knowledge areas (see Materials and methods). The most severe deficit was evident in knowledge on complications.

Table 1 CCKNOW scores for 100 IBD patients by type of disease, sex, age, education, disease duration, and self-estimated level of suffering from disease

	Total number	Mean score	SD
Disease			
UC	86	4.5	3.3
CD	9	5.2	4.8
Indeterminate	5	5.3	4.9
Sex			
Male	36	3.4	2.9
Female	64	5.4	3.7
Age			
<21 years	5	4.2	5.3
21–30 years	29	4.8	3.3
31–40 years	36	5.1	3.7
41–50 years	16	5.1	3.6
>50	14	3	2.4
Education			
Below high school education	18	2.1	1.9
Finished high school	37	5.3	3.4
2-Year university education	8	3.9	3.0
Bachelor degree	32	5.8	4.0
Masters degree or higher	5	3.0	2.0
Disease duration (years)			
1–5	60	4.4	3.5
6–10	22	4.0	3.3
11–15	6	7.5	1.9
16–20	6	7.2	5.0
>21	6	4.0	3.0
Level of suffering from disease			
Not at all	5	3.4	2.5
Little	15	5.5	4.1
Somehow	35	4.5	3.6
Much	26	4.6	3.5
Very much	19	4.7	3.5

Discussion

Though there are several studies on assessment of the level of disease-related knowledge among IBD patients in developed communities, it seems that there is still no data from developing countries. In addition, there is scanty data on health information preferences of the IBD patient in a developing country. The reason may be the weaker infrastructure and different priority settings of health administration and research systems of developing countries compared with that in the developed world. In fact, the top health priority in many developing countries is still WHO primary health care (PHC) issues such as increasing infants' immunization coverage and fighting infectious diseases and malnutrition.

This study was performed in a referral outpatient gastroenterology clinic in central Tehran (Iranian capital), owned by a famous gastroenterologist where patients from all parts of the capital and even many parts of the country presented. The main purpose of the study was to provide a first report from a developing country like Iran on the level of self-rated knowledge of disease among IBD patients. Determining the areas of knowledge deficit, any relationships of level of knowledge, and demographic features as well as favorite knowledge topics and health information preferences of Iranian IBD patients were among other goals of the study. The information was also to be employed in future patient education programs such as developing an interactive patient education website for Iranian IBD patients in Persian language (at the time this article was written, the aforementioned web site was developed and launched at http://www.ibd.ir by the funding body of this research).

Table 2 Favorite disease-related knowledge topics in 100 IBD patients by sex and type of IBD

	All (%)	M no. (%)	F no. (%)	UC no. (%)	CD no. (%)	Indeterminate no. (%)
Anatomy of gastrointestinal system	36	13 (36)	23 (36)	31 (36)	3 (33)	1 (20)
Cause	89	32 (89)	57 (89)	77 (90)	8 (89)	4 (80)
Symptoms	50	19 (53)	31 (48)	43 (50)	4 (44)	3 (60)
Medications	61	27 (64)	34 (53)	52 (60)	5 (56)	4 (80)
Drug complications	79	30 (83)	49 (77)	70 (81)	4 (44)	5 (100)
Nonmedication therapies	59	19 (53)	40 (63)	51 (59)	5 (56)	3 (60)
Surgery	39	14 (39)	25 (39)	36 (42)	2 (22)	1 (20)
Prevalence	25	7 (19)	18 (28)	23 (27)	1 (11)	1 (20)
Nutrition	69	25 (69)	44 (69)	58 (67)	7 (78)	4 (80)
Diagnosis	36	12 (33)	24 (38)	32 (37)	2 (22)	2 (40)
Complications	51	16 (44)	35 (55)	47 (55)	3 (33)	1 (20)
IBD effect on fertility, pregnancy, and breast feeding	29	5 (14)	24 (38)	27 (31)	1 (11)	1 (20)

UC Ulcerative colitis, *CD* Crohn's disease

In our study, the mean and median of CCKNOW score of the patients were 4.65 and 4.0 (out of 24), respectively. Using the 24-item CCKNOW, Eaden et al. [11] found a mean (median) score of 12.4 (12.5) and 12.6 (12.0) in 96 UC and 86 Crohn's patients, respectively. These patients were the members of a patient self-help group [the National Association of Crohn's and Colitis (NACC)] in Britain. They also found the same figures to be 7.9 (8.0) and 7.8 (7.5) in 104 UC and 68 Crohn's patients who were not NACC members. In a study by Eaden et al. [24] on 42 patients with colorectal cancer complicating UC and 44 age- and sex-matched IBD patients without colorectal cancer using 24-item CCKNOW, a mean of 8.2 and 8.3 was found for the two groups, respectively. Quan et al. [25] in the USA studied the effect of workshops on IBD patients' and their relatives' knowledge using a 30-item CCKNOW score and found a mean score of 18 (out of 30) for 59 IBD patients (and their close relatives) before entering patient education workshops. It is evident that our patients' scores were significantly lower. No doubt, better quality of health services in the developed world, especially the established role of physicians and specialized nurses as patient educators and higher access to web-based material in patients' native language, can partly explain this. The effect of patients' self-help groups and wider availability of published material in developed countries may be other factors causing such difference.

CCKNOW questionnaire can well assess four areas of knowledge in IBD (Table 4). An alerting finding in our patients, in addition to ubiquitously low scores in all fields, is the fact that the most severe knowledge deficit was on the complications of IBD. Though this finding was confirmed in other studies by Quan et al. [25] and Eaden et al. [24], the deficit was more severe in our patients. For example, only 5% of our patients knew that those with prolonged IBD are at risk of cancer, while 17.8% of the subjects in the study of Quan et al. [25] and 23% in the study of Eaden et al. [24] were aware of this. This knowledge deficit on IBD complications may have disastrous aftermaths such as underestimation of the importance of colorectal cancer screening.

Similarly, our patients suffered from a severe knowledge deficit in general IBD knowledge such as the anatomy of gastrointestinal system. Only 7% of our patients knew the location of terminal ileum, while the same figure was 54.2% in Quan et al. [25] and 35% in Eaden et al. [24] studies. Knowledge of gastrointestinal anatomy can be important in patient-aided decision making when considering different surgical treatments. Within our subjects, the knowledge in diet and medications fields seemed slightly better than that of general IBD and complications, though both were lower than the knowledge of the patients in the other two studies. Table 3 shows a comparison of the percentage of correct answers to each question among our patients and that in Quan et al. and Eaden et al. studies. In Quan's study, the percentages belonged to all 743 subjects (including IBD patients and their relatives) before entering patient education workshops. The percentages of correct answers to all questions in the study of Quan et al. were higher than that of our subjects except for one question which asked whether azathioprine is an immunosuppressive drug. Not all correct-answer percentages of the study by Eaden et al. were available; however, those available are shown in Table 3. It is noteworthy that half of the cases of the study by Eaden et al. [24] were UC patients with colon cancer. There were also some differences between our study and that of Quan et al. [25]. First, their subjects included not only IBD patients but also some of their relatives. However, they mentioned in their study that patients' scores and correct answer percentages were slightly better than relatives; this does not seem to disrupt our comparisons. Moreover, they used 30-item CCKNOW questionnaire, so the reader is recommended to consider this point when comparing their mean CCKNOW score

Table 3 Percentage of correct answer to each question in CCKNOW questionnaire in 100 IBD patients in our study and a comparison with the results from Quan et al. [25] and Eaden et al. [24]

No.	Question	This study	Quan et al. [25][a]	Eaden et al. [24][b]
1	Patients are allowed to eat dairy products	64	89.4	–
2	Elemental feeds are very easy to digest	4	40	–
3	Proctitis is a form of colitis that affects the rectum or back passage only	6	41	–
4	Being symptom-free for 3 years does not mean IBD is cured	26	82.5	71
5	IBD runs in families	35	66.6	22
6	Inflammation can occur in other parts of the body as well as the bowel	36	63.8	36
7	A fistula is an abnormal track between two pieces of bowel or between the bowel and skin	16	61.5	33
8	The terminal ileum is a section of the bowel just before the anus	7	54.2	35
9	During a flare up of IBD, the platelet count in the blood rises	5	11.7	–
10	Steroids can be given in the form of an enema into the back passage	16	36.7	53
11	Immunosuppressive drugs are given to IBD patients to reduce inflammation in the bowel	39	50.9	56
12	Sulfasalazine is used to reduce the frequency of flare-ups	37	59.6	64
13	Azathioprine is an immunosuppresive drug	25	20.9	12
14	A woman with Crohn's disease may find it more difficult to become pregnant	8	21.9	–
15	Ulcerative colitis is common in Europeans and North Americans	19	34.9	–
16	Male patients who take sulfasalazine have reduced fertility levels that are reversible	5	18	–
17	The length of the small bowel is approximately 6 m	23	39.6	–
18	The function of the large bowel is to absorb water	28	46.8	–
19	Another name for an ileorectal anastomosis operation with formation of a reservoir is pouch	3	38.8	–
20	If terminal ileum is removed during surgery, the patient will have impaired absorption of vitamin B12	8	39.9	–
21	Patients with IBD which has lasted for 8–10 years need to be screened for cancer of the colon	5	17.8	23
22	There are millions of tiny "hairs" in the small bowel to increase the absorptive surface, which are called villi	5	61.2	–
23	Headache is not a common symptom of IBD	38	63.1	–
24	A child who has IBD probably will not be as tall as his or her friends	6	48.9	15

All figures are percentages
En dash indicates that the data regarding these items were not retrievable from the study by Eaden et al. [24]
UC Ulcerative colitis, *CD* Crohn's disease
[a]The data from Quan et al. [25] includes the percentages of correct answers from 743 individuals, including IBD patients and their close relatives before entering patient education workshops in the USA
[b]The study by Eaden et al. [24] included 42 cases of colorectal cancer complicating UC and 44 age- and sex-matched IBD patients without colorectal cancer

(18 out of 30) with that of ours (4.65 out of 24). It is noteworthy that CCKNOW developers (Eaden et al. [11]) recommend using the 24-item CCKNOW questionnaire for single-time knowledge assessment.

In a study by Marshal et al. [26] in 1979, it was claimed that knowledge level might be higher in a selected patient group: younger, professional, first recurrence, longer attendance at an IBD clinic, and perceived good general or mental health status. In 2000, O'Sullivan et al. [27] reported that age, sex, social class, anxiety, and depression status were not related to patients' self-rated level of knowledge. In 2002, having studied a group of UC patients with colorectal cancer and some age- and sex-matched IBD patients, Eaden et al. [24] found no statistically significant associations between 24-item CCKNOW scores and gender, age, and years spent in full-time education. Similarly, the same author had found no correlation between duration of IBD and CCKNOW score in 1999 [11]. Our study also measured some of the aforementioned relationships. Similar to Eaden's studies [11, 24], there was no statis-

Table 4 Disease-related knowledge areas assessed by CCKNOW questionnaire in IBD patients

Knowledge area	Related questions (no.)	Correct answers (%)
Diet	1 and 2 (2)	34
Medications	10–13 and 16 (5)	24
General IBD knowledge	3–5, 8, 9, 15, 17–19, 22, and 23 (11)	18
IBD complications	6, 7, 14, 20, 21, and 24 (6)	13
Total	1–24 (24)	100

The questions of each area and the percentage of correct answers for each area in 100 IBD patients are shown
IBD Inflammatory bowel disease

tically significant relationship between CCKNOW score (the level of knowledge) and age or duration of disease. In contrast, we found higher CCKNOW scores in women (p=0.006) and a weak positive correlation between the level of education and CCKNOW score (Spearman's ρ= 0.23, p=0.02).

The self-assessed level of suffering from disease was a factor that seems not to have been investigated in aforementioned studies. We wished to know whether a higher subjective perception of suffering from disease would cause the patient to be of a higher level of knowledge. Though correlation cannot be inferred as evidence for causality, finding a correlation might at least start suspicions for further studies. However, we did not find any correlations between the level of knowledge and self-assessed level of suffering. On the other hand, patients' perception when filling the questionnaire might have been different from their previous perception, and therefore, such estimations may not be of high accuracy.

Though the study revealed some interesting facts regarding the knowledge level and health information preferences of a population of IBD patients in Iran, some important issues regarding the study population must be addressed here to guide the reader to a more careful judgment of the presented data. This study was performed in an outpatient gastroenterology clinic located in the center of Iranian capital, Tehran. First, in Iran, there is not any strict referral systems (like that in UK for example) in which patients are automatically forced to see their family physician in their residential district before seeing a specialist. Iranian patients has the option to directly present for any medical complaint to any specialist they prefer. This especially holds true as to very famous doctors (as the one in this study), most of whom live in the capital. It is commonplace to see patients from any region of the country present for their medical problems to such famous physicians in the capital. Though some of them are referred by a general practitioner or another specialist, many may go to see a famous doctor because of his presence on TV health forums or simply after being recommended by a relative or a friend. Consequently, it is difficult to tell, for example, exactly what population a leader gastroenterologist in the capital with a crowded office is serving. In a survey performed in the same clinic a short while before this study, two thirds of the subjects were from the capital and its suburbs, while the remaining one third were mainly from other Iranian cities. This may at least justify limited extrapolation of data to urban population. Second, the educational status of the study population looks well above the average Iranian population. Compared to a survey on a sample of about 25,000 Iranians 10 years and older performed by Statistical Center of Iran in 2002 in which the education levels of the population were determined [28], the proportion of those having high school diploma or university education (sum of the two groups) in the country (32%) was less than half (40%) of that in our study population (82%). Whether IBD is more common in more educated Iranians is unknown. However, the higher-than-average education level of the study population is another point meriting attention when considering extrapolation of data. In short, the fact that the level of knowledge is significantly lower than the patients of the developed countries in this more urbanized and more educated population we studied and considering the weak positive correlation of education and CCKNOW score in our study makes it seem rather unlikely that the total population of Iranian IBD patients might achieve higher CCKNOW scores than that of our patients. Nevertheless, this remains to be fully confirmed by a more extensive study, including IBD patients from several provinces.

Another important question that may form in the mind of the reader is why such a big majority of 100 consecutive IBD patients in this study (86%) were patients with UC. Can this overt dominance of UC patients be a fortuitous event? Anecdotal evidence shows that UC is much more prevalent than CD in Iran. However, due to lack of well-formed and extensive population-based registries in Iran as in many other Asian countries [2], there is no data on real epidemiological indices of IBD and the relative prevalence of UC to CD in the country. A review article by Yang et al. [2] in 2001 gathered evidence on higher prevalence of UC compared to CD in some Asian and Middle East countries and also in Asian migrants living in Europe. In a recently published study by Firouzi et al. [29] in Iran, 382 of 428 consecutive cases with confirmed IBD (presenting to a university hospital and two private clinics in Tehran) were UC patients, while CD cases comprised only 46 of their cases. The ratio of UC/CD cases in the study of Firouzi et al. [29] (8.3) was quite similar to that in our study (9.5). Though these figures were confirming the anecdotal evidence from Iranian clinicians and those from the study of Yang et al. [2], they should never be used to infer the relative prevalence of UC to CD in Iran, and this issue can

be the focus of future population-based studies on the epidemiology of IBD in Iran.

Finally, some policy makers may criticize performing such knowledge assessment studies and other activities towards patient education for such diseases as IBD in developing countries where resources are usually limited and other priorities dominate. However, it is noteworthy that, in some still developing countries like Iran, good progress has been made towards the goals of PHC. After two decades of performing WHO's development plans, Iranians now benefit from a higher rates of access to health services. According to World Human Development Report 2004, there were 110 physicians per 100,000 people (1990–2003), 99% of 1 year olds were fully immunized against tuberculosis and measles (2002), 80 to 94% of the population had sustainable access to affordable essential drugs (1999), and 90% of births were attended by skilled health personnel (1995–2002) in the country [30]. Considering these facts, it does not seem imprudent to commence preliminary attempts to plan for some more sophisticated aspects of health care such as patient education.

Conclusion

While all patients in this study were inclined to know more about their disease, the level of disease-related knowledge in the IBD patients of this study was significantly lower than that of the patients in developed countries. The more profound knowledge deficit in the area of IBD complications may lead to disastrous aftermaths such as late diagnosis of colorectal cancer induced by prolonged IBD. Considering these as well as the positive effect of higher levels of disease-related knowledge of IBD patients on their quality of life, vigorous patient education programs for the Iranian IBD patient seems mandatory.

Further research, including larger samples, is suggested to better confirm the data from this study and also to investigate the higher knowledge levels among female IBD patients in the country. Disease-related favorite topics found in this study in addition to knowledge areas of higher deficit can be a good guide in the future patient education programs for IBD patients.

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