

# Disease-Related Knowledge and Information Needs Among Inflammatory Bowel Disease Patients in Korea

## ABSTRACT

The aim of this study was to identify disease-related knowledge and information needs of patients with inflammatory bowel disease. The 313 patients (Crohn disease:  $n = 169$ , colitis:  $n = 144$ ) presenting to an outpatient gastroenterology clinic of a tertiary care hospital in Seoul, Republic of Korea, were scored on their knowledge of Crohn disease and colitis and their information needs were assessed in the questionnaire. Patients with Crohn disease obtained a higher mean knowledge score than patients with colitis. The patients with Crohn disease had significantly higher scores about complications than patients with colitis. The patients with Crohn disease showed significantly higher mean scores relating to the patients' information needs than patients with colitis. The favorite topics of information needed were disease, medication, and diagnosis/operations. The patients with Crohn disease wanted more information than patients with colitis about medications used for treatment, daily life, and pregnancy. The effectiveness of the training and education given to patients can be maximized in this education system when the information about disease and medications for Crohn disease patients or information about disease and diet for colitis patients is primarily provided according to the degree of the patients' need for information.

Received July 26, 2013; accepted June 4, 2014.

**About the authors:** Yang-Sook Yoo, PhD, RN, is Professor, College of Nursing, Catholic University, Banpo-dong, Seocho-gu, Seoul, Republic of Korea.

Ok-Hee Cho, PhD, RN, is Assistant Professor, College of Nursing, Jeju National University, Jejudaehak-no, Jeju, Republic of Korea.

Kyeong-Sook Cha, PhD, RN, is Assistant Professor, Department of Nursing, Daegu Haany University, Sincheondong-ro, Suseong-gu, Daegu, Republic of Korea.

This research was supported by the Basic Science Research Program through the National Research Foundation of Korea (NRF) funded by the Ministry of Education, Science and Technology (20110012271). The authors thank Jayne A. Eaden, Keith Abrams, and John F. Mayberry for their permission to use the questionnaire (Crohn's and Colitis Knowledge score).

The authors declare no conflicts of interest.

This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 3.0 License, where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially.

**Correspondence to:** Ok-Hee Cho, PhD, RN, College of Nursing, Jeju National University, 690-756, 102 Jejudaehak-no, Jeju, Republic of Korea (ohcho@jejunu.ac.kr).

DOI: 10.1097/SGA.000000000000063

Inflammatory bowel disease (IBD) encompasses both Crohn disease (CD) and ulcerative colitis (UC), chronic relapsing disorders of unknown etiology. The incidence of IBD in foreign nations varies by region. The highest annual incidence of UC per 100,000 individuals was 24.3 in Europe, 6.3 in Asia and the Middle East, and 19.2 in North America. The highest annual incidence of CD per 100,000 individuals was 12.7 in Europe, 5.0 in Asia and the Middle East, and 20.2 in North America (Molodecky et al., 2012).

The incidence rate of CD in Korea in 1986 and 2008 sharply increased from 0.05 to 5.1 per 100,000 people, and UC from 0.34 to 5.4 (Shin et al., 2011; Yang et al., 2008). It has been postulated that this phenomenon may be related to the Westernization of lifestyles, including changes in dietary habits and environmental changes (Thia, Loftus, Sandborn, & Yang, 2008).

With onset in early adult life, IBD is a chronic illness that, when active, presents with symptoms including abdominal pain, gastrointestinal bleeding, diarrhea, and weight loss. These often unpredictable symptoms can have a severe effect on the social, emotional, and physical well-being of patients (Magro et al., 2009).

Inflammatory bowel disease is a disease characterized by the alternating periods of remission and relapse of active symptomatic disease from the moment of diagnosis for the rest of life, and patients should learn how to cope with the problems arising from the disease. However, because of lower incidence rates and prevalence in Asian countries, such as Korea and China, compared with Western countries, there is a lack of social support and resources to help patients with IBD, and systematic self-management-related educational materials or programs have yet to be developed sufficiently.

Disease-specific information is increasingly being recognized as important for patients as it improves compliance with therapy and satisfaction with their overall care (Molenaar et al., 2001; Whelan et al., 2004). As can thus be expected, patients with a perceived lack of disease-related information have poorer health-related quality of life than their peers, manifested by higher frequency of disease-related worries and concerns in this group (Moser et al., 1995). Previous studies have shown that patients who receive information related to their disease are less anxious, more compliant, and more satisfied with their treatment and have a reduced number of physician visits and lower patient cost (Molenaar et al., 2001; Whelan et al., 2004). Appropriate knowledge and information enable the effective coping of patients before they visit doctors (Casellas, Fontanet, Borrue, & Malagelada, 2004).

In advanced Western nations, some studies have been performed on the knowledge and education demands related to IBD disease. But, with respect to these topics, there were no similar reports for Korean patients with IBD even though the incidence of IBD has rapidly increased in Korea.

The purpose of this study was, first, to determine the difference in disease-related knowledge and information needs according to the general characteristics of IBD patients, and second, to compare the difference in knowledge and information needs of CD and UC patients.

## Methods

### Design and Sample

We carried out a cross-sectional survey to identify disease-related knowledge and information needs of IBD patients. This study was approved by the Asan Medical Center's institutional review board. Participants were recruited from an outpatient gastroenterology clinic of Asan Medical Center, a tertiary care hospital, in Seoul, Republic of Korea, from September 2011 to January 2012. Patients provided informed consent and were asked to fill out a self-assessed questionnaire after their gastroenterology visit. For all patients diagnosed with

either CD or UC, their diagnosis had been confirmed by endoscopy, radiography, and/or histologic examination. The exclusion criteria were age less than 18 years, lack of cooperation, and diagnosed psychiatric illness.

## Measures

### Demographic Characteristics

Demographic information included gender, age, education, and occupation, and disease-related data through questions about the disease including disease type (CD and UC), IBD duration, previous history of operations, subjective health status related to the symptoms, and experience of education about IBD.

### Crohn's and Colitis Knowledge

The 24-item Crohn's and Colitis Knowledge (CCKNOW) score (Eaden, Abrams, & Mayberry, 1999), used with permission of its developer, was translated into Korean. The source text was translated by two nursing professors who were fluent in both Korean and English, and back-translated by an English professor. The final translation was completed by comparison of the back-translated text and the source text to check for meaning alterations.

We chose this questionnaire because it examines knowledge from multiple aspects, and because of its reliability and validity in assessing disease-related knowledge of IBD patients. Also, it assesses different areas of knowledge and detects the area of knowledge deficit. The questionnaire assesses four areas of knowledge regarding IBD management, these being general IBD knowledge (11 questions), diet (2 questions), treatment (5 questions), and IBD complications (6 questions). Scoring for CCKNOW is one point for each correct answer, and the maximum possible score is 24. Higher CCKNOW scores indicate better IBD-related knowledge. Cronbach's alpha coefficient for the CCKNOW score was found to be .85.

### Information Needs

An information needs questionnaire was crafted through literature review of the information needs of IBD patients. The questionnaire included the facilitation of secure Web messaging between patients and clinicians via anonymized frequently asked questions in the homepage of the research hospital. The questionnaire include 44 items assessing eight areas of information, including general information of the disease (six questions), medication (nine questions), diagnosis/operations (eight questions), diet (five questions), daily life (eight questions), and pregnancy (eight questions). The questionnaire asked the subjects to rate the eight areas of information on a 5-point Likert scale to measure how much information the patients felt they

wanted to know about each of these areas. The questionnaire was verified for content and construct validity by five experts (a gastroenterologist, two nursing professors, two specialized gastroenterology nurses, and one IBD patient with a master's degree). After a pilot questionnaire was performed to test for ambiguity and ease of completion, the questionnaire was modified and supplemented. Cronbach's alpha coefficient for the scale was acceptable at .94.

## Data Analysis

The mean CCKNOW scores and information needs scores were calculated for independent or related groups as appropriate. The difference in knowledge and information needs was compared using the *t* test and ANOVA. Duncan's multiple test was used to compare the CCKNOW scores and the patients' age, IBD duration, and subjective health status related to symptoms. The four areas of knowledge were separately analyzed and expressed in percentages for all patients. All statistical analyses were performed using SAS 9.0 (SAS Inc., Cary, NC).

## Results

### General Characteristics of the Subjects

Approximately 54% of all the 313 subjects had CD and 46% had UC. About 59.4% were male, 69.0% were below age 40 years, 65.5% were university graduates and above, and 60.1% had jobs. In addition, 60.1% had a previous history of IBD-related operations, and 62.3% had disease duration of 6 years and more. About 22.4% responded "little" or "not at all" to the question on subjective health status related to IBD symptoms, and 48.2% had experience of education about IBD.

### Disease-Related Knowledge and Information Needs According to General Characteristics

The mean score of the subjects' degree of knowledge was 9.5 out of 24; the mean score of the CD patients was 10.0, which was higher than that of the UC patients (8.8). The degree of knowledge of the subjects aged 50 years and older was lower than that of the subjects below the age of 50 years; it was also lower in high-school graduates than in university graduates, and lower in subjects with duration less than 1 year than in those with duration 6 years and more. The subjects who responded "not at all" or "very much" to the question on subjective health status related to IBD symptoms had a lower degree of knowledge than those who responded "little," and those who had no experience of education about IBD had a lower degree of knowledge than those who did have experience.

The mean score of the subjects' information needs was 194.5 out of 220, and the score of the information demands of the CD patients was 197.1, which was higher than that of the UC patients (190.7). The degree of information needs was higher in females than in males, in younger patients than in older patients, and in university graduates than in high school graduates (Table 1).

### Difference in Disease-Related Knowledge of CD Patients and UC Patients

The degree of knowledge of the subjects ranged widely from 11.2% to 86.3%, according to the questions, and 14 of the 24 questions showed fewer than 50% correct answers.

Among the IBD general knowledge questions, the question (Q3) on proctitis showed a higher percentage of correct answers in UC patients than in CD patients, but the questions (Q8, Q17, Q22) on anatomy showed a higher percentage in CD patients than in UC patients.

There was no difference in the percentage of correct answers between CD patients and UC patients in the area of knowledge about diet. Regarding treatment, the question (Q10) on steroids showed a higher percentage of correct answers in UC patients than in CD patients, but the question (Q13) on azathioprine showed a higher percentage of correct answers in CD patients. On the area of knowledge about IBD complications, the percentage of correct answers of CD patients was generally higher than that of UC patients (Table 2).

### Difference in Information Needs of CD Patients and UC Patients

CD patients and UC patients had the highest information needs for the disease. Patients with CD had higher information demands than UC patients in the areas of medication, daily life, and pregnancy (Table 3).

## Discussion

Recently, the incidence of IBD has been rapidly increasing in Korea, but the development of a systematic educational resource or program management for IBD patients is still insufficient. This study is the first attempt to determine the health-related knowledge and information demands of IBD patients in Korea, and it is expected to provide baseline data for the development of programs for the follow-up management of IBD patients in Korea.

The degree of knowledge of the subjects in this study was below average, 10.0 for CD patients and 8.8 for UC patients, out of a maximum score of 24. Using the 24-item CCKNOW, a study of patients belonging to self-help groups (the National Association of Crohn's and Colitis) in Britain found that the mean score of overall knowledge was 12.4 for UC and

**TABLE 1.** Knowledge and Information Needs by General Characteristics (*N* = 313)

Characteristic	Total, <i>n</i> (%)	Knowledge		Information Needs	
		<i>M</i> ± <i>SD</i>	<i>F/t</i> ( <i>p</i> )	<i>M</i> ± <i>SD</i>	<i>F/t</i> ( <i>p</i> )
<b>Disease</b>					
Crohn disease	169 (54.0)	10.0 ± 4.7	2.30	197.1 ± 19.5	2.54
Ulcerative colitis	144 (46.0)	8.8 ± 4.8	(.022)	190.7 ± 22.2	(.012)
<b>Gender</b>					
Male	186 (59.4)	9.1 ± 4.9	−1.77	192.2 ± 20.3	−2.06
Female	127 (40.6)	10.0 ± 4.4	(.078)	197.4 ± 21.4	(.040)
<b>Age (years)</b>					
18–29	115 (36.7)	9.5 ± 4.6 <sup>a</sup>	3.10	200.3 ± 16.1 <sup>a</sup>	10.18
30–39	101 (32.3)	10.2 ± 4.4 <sup>a</sup>	(.027)	194.4 ± 20.3	(<.001)
40–49	64 (20.5)	9.3 ± 5.4 <sup>a</sup>	<i>a</i> > <i>b</i>	188.2 ± 22.5 <sup>b</sup>	<i>a</i> > <i>b</i> > <i>c</i>
≥50	33 (10.5)	7.3 ± 4.4 <sup>b</sup>		177.4 ± 28.4 <sup>c</sup>	
<b>Education</b>					
High school	108 (34.5)	8.1 ± 4.6	−3.63	189.6 ± 25.8	−2.74
≥university education	205 (65.5)	10.2 ± 4.7	(<.001)	196.8 ± 17.4	(.007)
<b>Occupation</b>					
Yes	188 (60.1)	9.6 ± 4.8	0.54	194.3 ± 19.9	−0.07
No	125 (39.9)	9.3 ± 4.8	(.589)	194.5 ± 22.3	(.943)
<b>Operation</b>					
Yes	188 (60.1)	9.8 ± 4.6	−1.46	195.0 ± 20.7	−0.60
No	125 (39.9)	9.0 ± 5.0	(.144)	193.5 ± 21.2	(.550)
<b>Disease duration (years)</b>					
<1	35 (11.2)	7.3 ± 3.8 <sup>a</sup>	4.22	192.5 ± 21.1	0.76
1–5	83 (26.5)	8.8 ± 4.3	(.006)	193.6 ± 24.3	(.517)
6–10	110 (35.1)	9.9 ± 5.1 <sup>b</sup>	<i>a</i> < <i>b</i>	196.9 ± 20.2	
>10	85 (27.2)	10.3 ± 4.8 <sup>b</sup>		192.6 ± 17.6	
<b>Subjective health status related to symptom</b>					
Not at all	28 (9.0)	8.3 ± 4.7 <sup>a</sup>	2.44	195.8 ± 19.7	0.88
Little	42 (13.4)	10.7 ± 4.5 <sup>b</sup>	(.047)	196.8 ± 19.1	(.475)
Somehow	141 (45.1)	9.9 ± 4.5	<i>a</i> < <i>b</i>	192.6 ± 23.6	
Much	69 (22.0)	8.8 ± 5.0		197.2 ± 16.6	
Very much	33 (10.5)	8.2 ± 5.3 <sup>a</sup>		190.1 ± 19.9	
<b>Experiences of education about IBD</b>					
Yes	151 (48.2)	10.1 ± 4.8	−2.42	196.0 ± 19.8	−1.32
No	162 (51.8)	8.8 ± 4.7	(.016)	192.7 ± 21.9	(.188)
Total		9.5 ± 4.8		194.5 ± 20.8	

Note. IBD = inflammatory bowel disease.

<sup>a,b,c</sup>Duncan’s multiple test.

**TABLE 2.** Differences of Correct Answers for Items of Knowledge Between Crohn Disease (CD) and Ulcerative Colitis (UC) Patients (*N* = 313)

Item		Correct Answer (%)			
		Total	CD (n = 169)	UC (n = 144)	$\chi^2$ (p)
General IBD knowledge					
Q3	Proctitis is a form of colitis that affects the rectum or back passage only.	18.5	11.2	27.1	12.9 (<.001)
Q4	Being symptom-free for 3 years does not mean IBD is cured.	86.3	86.4	86.1	0.0 (.943)
Q5	IBD runs in families.	22.4	26.4	18.1	2.9 (.913)
Q8	The terminal ileum is a section of the bowel just before the anus.	14.4	18.3	9.7	4.7 (.030)
Q9	During a flare-up of IBD, the platelet count in the blood rises.	26.8	27.8	25.7	0.2 (.674)
Q15	Ulcerative colitis is common in Europeans and North Americans.	62.0	59.8	64.6	0.8 (.381)
Q17	The length of the small bowel is approximately 6 m.	32.0	43.2	18.8	21.4 (<.001)
Q18	The function of the large bowel is to absorb water.	52.4	53.9	50.7	0.3 (.578)
Q19	Another name for an ileorectal anastomosis operation with formation of a reservoir is pouch.	16.6	17.2	16.0	0.1 (.779)
Q22	There are millions of tiny “hairs” in the small bowel to increase the absorptive surface, which are called villi.	54.3	61.5	45.8	7.7 (.005)
Q23	Headache is not a common symptom of IBD.	32.3	30.8	34.0	0.4 (.539)
Diet					
Q1	Patients are allowed to eat dairy products.	55.0	54.4	55.6	0.0 (.843)
Q2	Elemental feeds are very easy to digest.	24.6	27.8	20.8	2.0 (.153)
Treatments					
Q10	Steroids can be given in the form of an enema into the back passage.	31.6	17.8	47.9	32.7 (<.001)
Q11	Immunosuppressive drugs are given to IBD patients to reduce inflammation in the bowel.	53.7	52.1	55.6	0.4 (.538)
Q12	Sulfasalazine is used to reduce the frequency of flare-ups.	30.7	26.0	36.1	3.7 (.054)
Q13	Azathioprine is an immunosuppressive drug.	51.1	69.8	29.2	51.4 (<.001)
Q16	Male patients who take sulfasalazine have reduced fertility levels that are reversible.	11.2	8.9	13.9	2.0 (.161)
IBD complications					
Q6	Inflammation can occur in other parts of the body as well as the bowel.	78.3	86.4	68.8	14.2 (<.001)
Q7	A fistula is an abnormal track between two pieces of bowel or between the bowel and skin.	51.8	72.8	27.1	65.0 (<.001)
Q14	A woman with Crohn disease may find it more difficult to become pregnant.	22.4	30.2	13.2	12.9 (<.001)
Q20	If terminal ileum is removed during surgery, the patient will have impaired absorption of Vitamin B <sub>12</sub> .	14.7	16.6	12.5	1.0 (.311)
Q21	Patients with IBD that has lasted for 8–10 years need to be screened for cancer of the colon.	63.6	55.6	72.9	10.0 (.002)
Q24	A child who has IBD probably will not be as tall as his or her friends.	38.7	47.3	28.5	11.7 (<.001)

Note. IBD = inflammatory bowel disease.

**TABLE 3.** Differences of Information Needs Between Crohn Disease (CD) and Ulcerative Colitis (UC) Patients ( $N = 313$ )

Categories	Number of Items (Range)	CD ( $n = 169$ ), $M \pm SD$	UC ( $n = 144$ ), $M \pm SD$	$t$ ( $p$ )
Disease	6 (1–5)	4.7 $\pm$ 0.5	4.6 $\pm$ 0.7	1.22 (.225)
Medication	9 (1–5)	4.6 $\pm$ 0.6	4.4 $\pm$ 0.9	2.18 (.031)
Diagnosis/operation	8 (1–5)	4.5 $\pm$ 0.5	4.4 $\pm$ 0.6	0.76 (.448)
Diet	5 (1–5)	4.4 $\pm$ 0.7	4.4 $\pm$ 0.8	0.46 (.649)
Daily life	8 (1–5)	4.2 $\pm$ 0.7	4.0 $\pm$ 0.8	2.97 (.003)
Pregnancy	8 (1–5)	4.4 $\pm$ 1.0	4.0 $\pm$ 1.3	3.06 (.003)
Total	44 (44–220)	197.1 $\pm$ 19.5	190.7 $\pm$ 22.2	2.54 (.012)

12.6 for CD, but in a study of IBD patients not belonging to the National Association of Crohn's and Colitis, the mean score was only 7.9 for UC and 7.8 for CD (Eaden et al., 1999). In a study measuring the degree of IBD patients' knowledge before an education workshop in the United States (Quan, Present, & Sutherland, 2003), the mean score of a 30-item CCKNOW was 18 points. The CCKNOW scores of two studies conducted in developing countries were lower than this study's scores, with only 6.6 for UC and 8.0 for CD in Sri Lanka (Subasinghe, Wijekoon, Nawarathne, & Samarasekera, 2010) and 4.5 for UC and 5.2 for CD in Iran (Rezailashkajani, Roshandel, Ansari, & Zali, 2006). The knowledge scores of our patients were better than those of developing countries, but similar to or worse than those of Western populations.

The results showed that the higher the age, the lower the education level, and the shorter the disease duration, the lower the degree of knowledge demonstrated. The degree was also low in subjects who responded "not at all" or "very much" to the question on subjective health status related to IBD symptoms, as well as those who had no experience of education about IBD and those who were UC patients. This coincides with the results of precedent research (Subasinghe et al., 2010) that reported that the degree of knowledge was low in patients with UC, and in patients who were older, were unemployed, and had a lower level of education and shorter duration of disease.

As a result, lower age showed higher information needs because young age groups are engaged in active social activities and thus require more information for positive disease management. Moreover, female subjects had higher needs because they showed high interest in disease-related knowledge during their childbearing age, taking into account the crucial influence of the disease on pregnancy and childbirth (Mañosa et al.,

2013). University graduates also showed higher demands than high school graduates. This is because of their high need and motivation to actively manage their disease and directly participate in making treatment decisions as they have a higher level of education (Arora & McHorney, 2000). Therefore, when devising an educational approach, it is necessary that the health-related education be tailored to the individual characteristics and needs of the patients.

The degree of knowledge of the subjects ranged widely from 11.2% to 86.3% according to the question, and 14 of the 24 questions showed fewer than 50% correct answers. Patients with IBD are known to get most of their knowledge and information related to their disease from physicians (Bernstein et al., 2011; Butcher, Law, Prudham, & Limdi, 2011). But the time patients spend consulting with clinicians is very short in the Korean healthcare system. So clinicians cannot provide sufficient information and knowledge to their patients. For this reason, patients have expressed a need for more reading material and direct education from their physicians and other members of the IBD healthcare team (Borgaonkar, Townson, Donnelly, & Irvine, 2002). However, medical institutions of Korea, in which IBD is treated, are concentrated in metropolitan areas and large cities. For this reason, patients in the suburbs or rural areas have difficulties in getting appropriate healthcare services. Knowledge confers a sense of control and enhances the ability to cope with chronic disease. However, the degree of knowledge of the subjects in this study was generally at a low level. Therefore, by providing appropriate training and information to patients, the patients' knowledge about the disease can be enhanced.

In this study, among the general IBD knowledge areas, the question on proctitis showed a higher percentage of correct answers in UC patients than in CD

patients; by contrast, the questions on anatomy showed a higher percentage of correct answers in CD patients than in UC patients. This is because, unlike UC where infection is focused around the rectum, infection in CD may occur in the entire digestive system from the mouth to the large intestines (Yang et al., 2008). Thus, CD patients obtained relevant knowledge with more interest in the structure and functions of the gastrointestinal system than UC patients. Especially for CD patients, because patients' knowledge about the anatomy of the terminal ileum plays an important role when they make important decisions about surgical treatment, CD patients who are generally more likely to be in a situation in which they have to make a decision about surgery are considered to have received relative training.

In this study, the percentage of correct answers for the question (Q10) on steroids in the knowledge area of treatment was higher in UC patients than in CD patients, but the percentage of correct answers to the question (Q13) on azathioprine was higher in CD patients. This may be because steroids are used in relapse treatment or remission induction in UC treatment, by oral administration or direct intestinal administration (enema). However, azathioprine, which is an immunosuppressant, has no clearly established standard for UC treatment unlike in CD, where it is broadly used in remission induction or maintenance (Jang, 2007). Thus, UC patients may have had few opportunities for relative education during their treatment. It is this confusion and lack of knowledge about medications that results in noncompliance and patients turning to alternative remedies (Keohane & Shanahan, 2008). Therefore, accurate information about medications and continuing education about the long-term side effects of a prescribed medication should be provided to IBD patients.

The degree of knowledge about complications was significantly higher in CD patients than in UC patients. This result was similar to previous studies (Rezailashkajani et al., 2006; Subasinghe et al., 2010). Unlike UC, CD can cause inflammation throughout the digestive tract, and intestinal inflammation can involve the full thickness of the bowel wall. Its symptoms are more severe, and severe complications such as fistula, tear, and open abscesses occur. Patients with CD occasionally experience severe changes in disease states because of these complications and experience more surgeries for these complications (Magro et al., 2009), so they might be more interested in the disease and have more access to educational opportunities than UC patients.

Information needs were significantly higher in CD than UC. In particular, information about medications,

daily life, and pregnancy were demanded significantly more in CD than in UC. Unlike UC, CD usually occurs in patients aged 20 years to 40 years, and 25%–33% occurs before the age of 20 years. Also, CD patients experience severe physical symptoms and complications throughout life, in the active state and in remission (Dudley-Brown et al., 2009; Larsson, Löf, Rönnblom, & Nordin, 2008; Lix et al., 2008). Because of the nature of the disease, CD patients have more difficulties in social life or in schools than UC patients. Female patients with CD have fears related to pregnancy and childbirth because of continually having to take drugs and the changes in their health, and when CD is in an active state, they have practical difficulties during pregnancy and childbirth.

Providing appropriate knowledge about the diseases helps the patients manage their diseases and make decisions in the process of treatment. Moreover, suitable education improves patients' disease treatment and coping methods and reduces their anxiety (Blumenstein et al., 2013; Moradkhani, Kerwin, Dudley-Brown, & Tabibian, 2011).

Therefore, to help patients with IBD control and manage their diseases throughout their lives, the development of a systematic education program that considers the characteristics of each disease is required to provide them with accurate and useful information.

Based on the results of this study, a more effective outcome will be achieved if education on treatment and general knowledge of the disease is preferentially provided to patients. Furthermore, it is necessary to select the appropriate training media for effective education. It is known that if a great deal of oral training is conducted, the effect of education is low (Kessels, 2003). Therefore, it is necessary to prepare more effective training methods, involving pamphlets, Web-based materials, multidisciplinary teams, and specialized nurses' training.

This study has the following limitations. First, as this study was conducted on IBD patients visiting the outpatient clinic of a tertiary care hospital located in Seoul, its findings cannot be broadly interpreted. Second, as this study was based on adults aged 18 years and older with IBD, it is necessary to conduct future research on adolescents under the age of 18 years. Third, the disease knowledge and educational needs of the IBD patients according to their disease activity could not be determined.

## Conclusions

The degree of the subjects' knowledge was low as a whole. Especially in the case of UC, the degree was lower when subjects were older than 50 years, had lower levels of education, or had disease duration of

less than 1 year. Appropriate education must be provided in the area of nursing education so that IBD patients can obtain adequate knowledge of their disease, understand their disease actively, and adapt to their changed lifestyle. Therefore, systematic education about the disease is required to improve the knowledge of chronic IBD patients, increase adherence to treatment, and allow patients to carry on with their normal daily life by adapting to the disease so that they enjoy improved quality of life. When developing a training program, it is necessary to select fields of education that are required not only by the healthcare providers but also by the patients. Training effectiveness can be maximized in this education system when information about the disease and medications for CD patients or information about the disease and diet for UC patients are primarily provided according to the current knowledge status and needs of the patients. Moreover, information must be provided without temporal and geographic constraints through online distance learning. In terms of nursing research, a replication study must be conducted, targeting patients in regions with limited access to appropriate healthcare such as small- and medium-sized cities. On the basis of the results of this study, we propose future research to develop, apply, and evaluate a systematic educational program for IBD patients. ✪

## REFERENCES

- Arora, N., & McHorney, C. (2000). Patient preferences for medical decision making: who really wants to participate? *Med Care*, 38(3), 335–341.
- Bernstein, K. I., Promislow, S., Carr, R., Rawsthorne, P., Walker, J. R., & Bernstein, C. N. (2011). Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. *Inflammatory Bowel Diseases*, 17(2), 590–598.
- Blumenstein, I., McDermott, E., Keegan, D., Byrne, K., Ellison, M., Doherty, G., ... Mulcahy, H. (2013). Sources of information and factual knowledge in Europeans with inflammatory bowel diseases: A cross-cultural comparison between German and Irish patients. *Journal of Crohn's & Colitis*, 7(9), e331–e336.
- Borgaonkar, M. R., Townson, G., Donnelly, M., & Irvine, E. J. (2002). Providing disease related information worsens health-related quality of life in inflammatory bowel disease. *Inflammatory Bowel Diseases*, 8(4), 264–269.
- Butcher, R. O., Law, T. L., Prudham, R. C., & Limdi, J. K. (2011). Patient knowledge in inflammatory bowel disease: CCKNOW, how much do they know? *Inflammatory Bowel Diseases*, 17(10), E131–E132.
- Casellas, F., Fontanet, G., Borruel, N., & Malagelada, J. R. (2004). The opinion of patients with inflammatory bowel disease on healthcare received. *Revista Espanola de Enfermedades Digestivas*, 96(3), 174–184.
- Dudley-Brown, S., Nag, A., Cullinan, C., Ayers, M., Hass, S., & Panjabi, S. (2009). Health-related quality-of-life evaluation of Crohn disease patients after receiving natalizumab therapy. *Gastroenterology Nursing*, 32(5), 327–339.
- Eaden, J. A., Abrams, K., & Mayberry, J. F. (1999). The Crohn's and Colitis Knowledge Score: a test for measuring patient knowledge in inflammatory bowel disease. *American Journal of Gastroenterology*, 94(12), 3560–3566.
- Jang, B. I. (2007). Clinical update: Inflammatory bowel disease. *Yeungnam University Journal of Medicine*, 24(2, Suppl.), S221–S233.
- Keohane, J., & Shanahan, F. (2008). Are patients with IBD knowledgeable about the risks of their medications? *Inflammatory Bowel Diseases*, 14 (Suppl. 2), S70–S71.
- Kessels, R. P. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96(5), 219–222.
- Larsson, K., Löf, L., Rönnblom, A., & Nordin, K. (2008). Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. *Journal of Psychosomatic Research*, 64(2), 139–148.
- Lix, L. M., Graff, L. A., Walker, J. R., Clara, I., Rawsthorne, P., Rogala, L., ... Bernstein, C. N. (2008). Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflammatory Bowel Diseases*, 14(11), 1575–1584.
- Magro, F., Portela, F., Lago, P., Deus, J., Cotter, J., & Cremers, I., ... Association of Portuguese Patients With IBD. (2009). Inflammatory bowel disease: A patient's and caregiver's perspective. *Digestive Diseases and Sciences*, 54(12), 2671–2679.
- Mañosa, M., Navarro-Llavat, M., Marín, L., Zabana, Y., Cabré, E., & Domènech, E. (2013). Fecundity, pregnancy outcomes, and breastfeeding in patients with inflammatory bowel disease: A large cohort survey. *Scandinavian Journal of Gastroenterology*, 48(4), 427–432.
- Molenaar, S., Sprangers, M. A., Rutgers, E. J., Luiten, E. J., Mulder, J., Bossuyt, P. M., ... de Haes, H. C. (2001). Decision support for patients with early-stage breast cancer: Effects of an interactive breast cancer CD-ROM on treatment decision, satisfaction, and quality of life. *Journal of Clinical Oncology*, 19(6), 1676–1687.
- Molodecky, N. A., Soon, I. S., Rabi, D. M., Ghali, W. A., Ferris, M., Chernoff, G., ... Kaplan, G. G. (2012). Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology*, 142(1), 46–54.
- Moradkhani, A., Kerwin, L., Dudley-Brown, S., & Tabibian, J. H. (2011). Disease specific knowledge, coping, and adherence in patients with inflammatory bowel disease. *Digestive Diseases and Sciences*, 56, 2972–2997.
- Moser, G., Tillinger, W., Sachs, G., Genser, D., Maier-Dobersberger, T., Spiess, K., ... Gangl, A. (1995). Disease-related worries and concerns: A study on out-patients with inflammatory bowel disease. *European Journal of Gastroenterology and Hepatology*, 7(9), 853–858.
- Quan, H., Present, J. W., & Sutherland, L. R. (2003). Evaluation of educational programs in inflammatory bowel disease. *Inflammatory Bowel Diseases*, 9(6), 356–362.
- Rezaishkajani, M., Roshandel, D., Ansari, S., & Zali, M. R. (2006). Knowledge of disease and health information needs of the patients with inflammatory bowel disease in a developing country. *International Journal of Colorectal Disease*, 21(5), 433–440.
- Shin, D. H., Sinn, D. H., Kim, Y. H., Kim, J. Y., Chang, D. K., Kim, E. J., ... Kim, J. J. (2011). Increasing incidence of inflammatory bowel disease among young men in Korea between 2003 and 2008. *Digestive Diseases and Sciences*, 56, 1154–1159.



- Subasinghe, D., Wijekoon, N. S., Nawarathne, N. M., & Samarasekera, D. N. (2010). Disease-related knowledge in inflammatory bowel disease: Experience of a tertiary care centre in a developing country in South Asia. *Singapore Medical Journal*, *51*(6), 484–489.
- Thia, K. T., Loftus, E. V., Jr. Sandborn, W. J., & Yang, S. K. (2008). An update on the epidemiology of inflammatory bowel disease in Asia. *American Journal of Gastroenterology*, *103*(12), 3167–3182.
- Whelan, T., Levine, M., Willan, A., Gafni, A., Sanders, K., Mirsky, D., ... Dubois, S. (2004). Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA*, *292*(4), 435–441.
- Yang, S. K., Yun, S., Kim, J. H., Park, J. Y., Kim, H. Y., Kim, Y. H., ... Yang, S. H. (2008). Epidemiology of inflammatory bowel disease in the Songpa-Kangdong district, Seoul, Korea, 1986–2005: A KASID study. *Inflammatory Bowel Diseases*, *14*(4), 542–549.