ORIGINAL ARTICLE

INTESTINAL RESEARCH

Impact of inflammatory bowel disease on daily life: an online survey by the Korean Association for the Study of Intestinal Diseases

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Background/Aims: Inflammatory bowel disease (IBD) is a chronic disabling gastrointestinal disorder that diminishes the quality of life of the affected individuals. Limited data are available regarding the impact of IBD on the daily life of Koreans. **Methods:** Self-administered, computer-aided, internet-based questionnaires were distributed to members of a Korean patient organization for IBD from March to April 2013, by the Korean Association for the Study of Intestinal Diseases. **Results:** A total of 599 patients with IBD (387 with Crohn's disease [CD] and 212 with ulcerative colitis [UC]) were enrolled. The majority of patients (81%) expressed feelings of fatigue, weakness, and being worn out in their daily lives during times of flare; this percentage was reduced to 61% during remission. Respondents were absent from work or school for an average period of 18 days because of illness, within the first 6 months; the majority of respondents (64%) felt stressed about their absence. Forty-six percent of the respondents reported having received unfair comments at work, or having suffered discrimination. Forty-seven percent of the respondents felt that IBD had negatively affected their income and earnings. Compared with patients with UC, those with CD reported a more frequent negative impact of IBD on work, or more economic burden. More than half of the respondents (61%) reported that IBD had prevented them from making or keeping friends. **Conclusions:** IBD significantly impacts daily life, including work, education, and social relationships. Treatment that addresses the full spectrum of life of a patient would be more effective. **(Intest Res 2017;15:338-344)**

Key Words: Inflammatory bowel disease; Crohn disease; Colitis, ulcerative; Quality of life; Surveys and questionnaires

INTRODUCTION

Although the incidence rate of IBD in Asian countries is considerably lower than the rate in Western countries, the burden of IBD has been rapidly increasing in Korea.[1-3] However, public awareness about IBD is still low in Korea. Delay in the diagnosis of IBD could delay therapy, which can worsen the outcome.[4-7]

IBD mainly consists of UC and CD. These are chronic disabling gastrointestinal disorders that diminish the quality of life (QOL) of the patient.[5,8-10] Patients with IBD more frequently receive disability allowances than those received by age-matched individuals from the general population,[5,6,10] which proves the detrimental effects of IBD on health-related QOL and productivity.[5,8] A recent large-scale study (comprising 4,670 patients with IBD from 25 countries) conducted by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) reported the detrimental effects of IBD on intimate relationships, and the unfair comments received by the patients with regard to their work performance.[8]

However, limited studies have assessed the impact of IBD on the life of patients in Korea, with the majority of studies having been conducted in Western cohorts.[5,6,8-10] In addition, there is little public knowledge regarding IBD and the chronic suffering of patients in Korea.

To overcome these issues, the Korean Association for the Study of Intestinal Diseases (KASID) has been conducting the "Happy Bowel Campaign" since 2013 to raise public awareness of IBD in general and to provide accurate information regarding the importance of early diagnosis and proper treatment to patients with IBD. In addition, the KASID is a promoter of World IBD Day, held every year on May 19.

This study reports the findings of a KASID-sponsored survey that aimed to investigate the impact of IBD on the daily lives of patients in Korea.

METHODS

1. Study Population

Patients with UC or CD were enrolled. Self-administered, computer-aided, internet-based questionnaires were distributed to them by the KASID, from March to April 2013. The KASID advertised the study through the Korean IBD patient advocacy and support group newsletter and website, and through online advertisements during the Happy Bowel Campaign. The purpose of the study was explained to patients at the time of enrollment. The survey was anonymous and the data were analyzed without revealing the personal details of the patients. Patients who had no Internet access were excluded, since the survey was only available online. Responding to the survey questions was considered consent to participate.

2. Survey

The survey was designed by KASID members of the International Affairs Committee Secretary of Liaison & Public Relations in cooperation with a communications company "Communication Works." The survey was based primarily on the IMPACT survey of the EFCCA and on previously published reports[8] on the QOL of patients with IBD. The survey consisted of 68 questions divided into 6 categories: (1) demographics, (2) experience with IBD, (3) overall impact on life, (4) overall impact on work, (5) overall economic impact, and (6) impact on relationships (Supplementary Material 1).

Some questions regarding "flare" and "remission" were short-answer questions. Most questions were closed ended, and participants were allowed to select one applicable option. The extent of "flare" and "remission" was open to patient interpretation. The questions concerning the overall impact of IBD were measured using a 5-point Likert scale (strongly agree, 5; agree, 4; neither agree nor disagree, 3; disagree, 2; strongly disagree, 1). In these cases, disagree or strongly disagree represented "no" and the other responses represented "yes."

3. Statistical Analysis

The collected data were analyzed using SPSS for Windows version 22.0 statistical software (IBM Corp., Armonk, NY, USA). With regard to statistical accuracy, a range of ±2.53% (95% CI limits) was set. Descriptive statistics and multiple linear regression analysis were used to analyze the responses, with subanalyses of patients with CD and UC. Subgroup differences were calculated using the chi-square test.

4. Ethics

The study was approved by the Seoul National University Ethics Committee (number: E-1403-037-563), with the completion and return of the survey implying consent to participate.

RESULTS

1. Demographics

A total of 599 patients with IBD (387 [64.6%] with CD and 212 [35.4%] with UC) completed the survey. Demographic and baseline data for all respondents are shown in Fig. 1. The majority of respondents were male (69.6%) in both the

CD and UC subgroups. The majority of participants (59%) reported a period of more than 5 years since the diagnosis of IBD (60% of the patients in the CD subgroup and 57% of the patients in the UC subgroup).

2. Experience with IBD

Most respondents (84%) from the CD and UC groups reported IBD being chronically active, whereas 16% reported being in remission. Sixty-five percent of the patients had been admitted to a hospital for IBD within the 5 years preceding the study; however, the proportion of patients with

CD was significantly higher than the proportion of patients with UC (76%, $P<0.001$), with regard to the hospitalization. Thirty-eight percent of the patients received emergency care before being diagnosed with IBD. Eighteen percent of the respondents had experienced a surgical procedure because of IBD. More patients with CD than with UC reported this experience ($P<0.001$) (Table 1).

Forty-one percent of the respondents reported visiting a hospital 6 months after they noticed the first symptoms related to IBD. The time before the first hospital visit was significantly longer in patients with CD ($P<0.001$). The reasons for delayed hospital visit were lack of knowledge about IBD (75%), mild symptoms (13%), inconvenient hospital access (3%), economic burden (3%), and others (6%). Most respondents (75%) received a final diagnosis within a year after they first noticed the symptoms. The other 25% patients received a final diagnosis after more than a year; in 3% of these, IBD was diagnosed after 5 years from their first symptoms. The time required for final diagnosis was also significantly longer in patients with CD ($P<0.001$) (Table 1).

About three-quarters of the respondents reported undergoing current treatment by a gastroenterologist (75%), while 13% reported undergoing current treatment by a primary physician. The most commonly taken drug among the respondents was 5-aminosalicylates (69%), followed by immunosuppressive agents (48%), corticosteroids (15%), and biological drugs (11%). More patients with CD than with UC were being treated with biological drugs (15% and 5%, respectively) at the time of conducting the study. Sixty-one
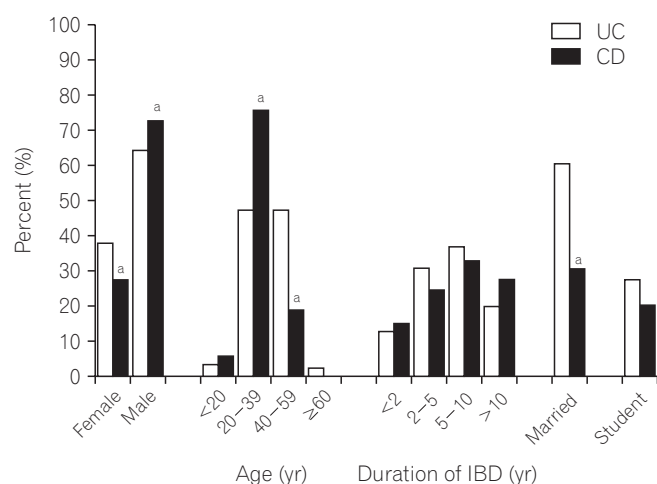

Fig. 1. Baseline characteristics of patients with IBD. [a]$P<0.05$, compared with patients with UC.

Table 1. Experience with IBD

	CD (n=387)	UC (n=212)	*P*–value
Current status of IBD			
Chronically active condition	325 (84)	178 (84)	1.000
In remission	62 (16)	34 (16)	1.000
Hospitalization in the past 5 yr	294 (76)	98 (46)	<0.001
Emergency care before diagnosis of IBD	186 (48)	40 (19)	<0.001
Previous surgeries owing to IBD	190 (49)	13 (6)	<0.001
Time to hospital visit since noticing first symptoms (mo)			
<6	208 (54)	145 (68)	<0.001
≥6	179 (46)	67 (32)	<0.001
Time required to receive the final diagnosis since noticing the first symptoms (mo)			
<6	199 (51)	144 (68)	<0.001
6–12	77 (20)	29 (14)	0.058
>12	112 (29)	38 (18)	0.003

Values are presented as number (%).

percent of the patients had experienced side effects from corticosteroids, and 87% of the patients were concerned about the long-term effects of corticosteroids.

3. Overall Impact of IBD on Life

The majority of patients (81%) expressed feelings of fatigue, weakness, and being worn out in their daily lives during times of flare; this percentage was reduced to 61% during remission. Most patients (68%) felt stressed and were psychologically affected even during remission. Thirty-seven percent of the patients reported that they felt like committing suicide (CD 41% vs. UC 30%, *P*=0.01). Multiple linear regression analysis revealed that previous emergency care (*P*=0.021), previous hospitalizations (*P*=0.036), previous surgeries (*P*=0.035), experience of abdominal pain (P=0.008), and using biologics (*P*=0.020) were associated with the feeling of committing suicide. Most patients (74%) were anxious about their future (Table 2). Young age (*P*=0.047), low income (*P*=0.026), and experience of abdominal pain (*P*<0.001) were associated with anxiety about the future, as per multivariable regression analysis.

4. Overall Impact of IBD on Work

More than half (52%) of the respondents reported absence from work or school because of illness within the past 6 months (mean, 18 days). Younger patients and patients with CD had had more sick days; the mean period absence owing to sickness was 10 days for those >40 years of age and 23 days for those <40 years of age (*P*<0.001), and 20 days versus 14 days for patients with CD and UC, respectively (*P*<0.001). The absence from work/school owing to IBD caused stress in 64% of the respondents. Compared to patients with UC, those with CD reported a more frequent negative impact of IBD on work (Table 3). The use of biologics (*P*=0.007) and steroids (*P*=0.001), previous hospitalization (*P*=0.043), previous surgeries (*P*=0.009), and abdominal pain (*P*=0.001) were associated with the negative impact of IBD on work, as per multiple linear regression analysis.

5. Overall Economic Impact of IBD

Forty-one percent of the respondents reported decreased QOL owing to the economic burden caused by IBD. Twenty-one percent of the respondents had stopped medical treat-

Table 2. Overall Impact of IBD on Daily Life

	CD (n=387)	UC (n=212)	*P*–value
Felt tired, weak, and worn out in daily life during flare-ups	311 (80)	174 (81)	0.664
Felt tired, weak, and worn out in daily life during remission	238 (61)	127 (60)	0.727
Felt stressed and psychologically affected during remission	270 (69)	137 (64)	0.201
Having felt like committing suicide	158 (41)	64 (30)	0.010
Having felt anxiety about the future	302 (78)	141 (67)	0.003

Values are presented as number (%).

Table 3. Overall Impact of IBD on Work

	CD (n=387)	UC (n=212)	*P*–value
Cancelled or rescheduled an appointment	238 (62)	121 (57)	0.297
Left office or school early	220 (57)	80 (38)	<0.001
Absence from work or school	228 (59)	83 (39)	<0.001
Felt stress about taking time off work or school	271 (70)	112 (53)	<0.001
Received unfair comments at work or school	155 (40)	52 (25)	<0.001
Suffered discrimination or were ostracized	52 (14)	14 (7)	0.010
Decline in income or academic ability	200 (52)	80 (38)	0.010
Unable to perform to their full potential	252 (66)	119 (56)	0.035

Values are presented as number (%).

Table 4. Overall Economic Impact of IBD

	CD (n=387)	UC (n=212)	*P*–value
Stopped medical treatment owing to economic burden	96 (25)	30 (14)	0.002
IBD had negatively affected the income	201 (52)	180 (38)	<0.001
Sorry for the family bearing treatment cost	244 (63)	79 (37)	<0.001
Decreased quality of life owing to the economic burden	170 (44)	77 (36)	0.082

Values are presented as number (%).

Table 5. Impact of IBD on Relationships

	CD (n=387)	UC (n=212)	*P*–value
Prevented from making or keeping friends	237 (62)	126 (59)	0.663
Had to end an intimate relationship end owing to IBD	182 (47)	100 (47)	1.000
Felt stressed about keeping intimate family relationships	155 (40)	85 (40)	1.000
Meeting others with IBD made them more optimistic	120 (31)	67 (32)	0.927
Patient association had a beneficial impact on their life	258 (67)	161 (76)	0.020

Values are presented as number (%).

ment because of the economic burden. Those with CD reported an economic burden more often than those with UC (Table 4). Male gender (*P*=0.001), old age (*P*=0.011), low income (*P*=0.008), use of steroids (*P*=0.039) and biologics (*P*=0.023), previous hospitalization (*P*=0.048), and previous surgeries (*P*=0.002) were associated with high economic burden, as per multivariable regression analysis.

6. Impact of IBD on Relationships

Sixty-one percent of the patients reported that IBD had prevented them from making or keeping friends. Nearly half of the respondents (47%) reported having had to end an intimate relationship owing to IBD. Most of the respondents (70%) reported that the patient association had a beneficial impact on their life (Table 5). Young age (*P*=0.002), previous surgeries (*P*=0.003), and previous hospitalization (*P*=0.038) were associated with the negative impact of IBD on relationships, as per multivariable regression analysis.

DISCUSSION

IBD is typically diagnosed in childhood or early adulthood, and is a lifelong condition.[5,8-10] Although IBD does not reduce life expectancy, it has a substantial impact on health-related QOL.[8,11,12] The present study reports the experience of IBD among Korean patients and the impact of IBD on their daily life. Most patients with IBD were tired, weak and worn out

in their daily life during a remission as well as during flare-ups. A large number of patients reported that IBD adversely affected their QOL. This negative impact of IBD was more severe in patients with CD than in those with UC. A previous experience of surgeries, and hospitalization due to IBD were associated with this negative impact. In general, chronic fatigue has been found to be more prevalent in patients with IBD than in healthy subjects,[9,13,14] which, in turn, diminishes the health-related QOL in IBD.[9] Accordingly, physicians should remember that fatigue is an important symptom of IBD that impacts the health-related QOL of the patients.

In this study, the time from onset of symptoms of IBD to hospital visit was long; over 41% of the patients had been symptomatic for at least 6 months before visiting a clinician. The most common cause of delayed hospital visit was lack of patient's knowledge about the disease. In addition, although most responders reported establishment of a final diagnosis within 12 months after noticing the first symptoms, 25% of the patients waited for more than a year for the final diagnosis. The delay in meeting a specialist and emergency department visit was more striking for patients with CD than for those with UC. Population-based cohort studies reported that one-fifth to one-third of the patients with CD have complications such as stricture, abscess and/or fistula at the time of diagnosis.[15,16] Functional gastrointestinal disorders such as IBS often mimic early manifestations of IBD, and infectious diseases such as intestinal tuberculosis, which mimic IBD, can hinder accurate assessment of the disease

in Korea, thereby delaying hospital visit or referral to IBD specialists.[7,17,18] In the IMPACT survey, only 54% of the 4,670 patients received a final diagnosis within 1 year after noticing the first symptoms. About 20% of the patients received a final diagnosis after more than 5 years. The majority of patients (67%) had visited an emergency department at least once before their diagnosis.[8] Timely diagnosis and treatment would help reduce the health care burden of hospitals, including prediagnosis hospital visits or admissions.[8,19] Patients with IBD tend to require emergency room or primary clinic care prior to diagnosis; thus, awareness about IBD is necessary among emergency care staff or primary physicians.[8]

About 15% of the respondents received corticosteroid therapy, which was a concern for most of them. Corticosteroid use should be consistent with the guidelines, and the advantages and possible detrimental effects should be discussed with patients.[8,20-22]

The fluctuations and unpredictable exacerbations of IBD symptoms have a significant psychological impact on the patient's life. Fears related to the long-term effects of treatments, and the progression of the disease can exacerbate anxiety and depression.[11,23-25] In the present study, 37% of the patients reported having felt like committing suicide. Most patients were anxious about their future. The prevalence of anxiety and/or depression in patients with IBD has been reported to be 35% during remission;[24] the prevalence of anxiety and depression during relapse has been reported to be 80% and 60%, respectively.[25] In a recent study, Korean patients with IBD showed higher levels of depression and impaired health-related QOL than those shown by healthy controls.[26] The negative perceptions of IBD among patients and the depressive mood can increase treatment nonadherence, leading to a poorer outcome.[19] Integrating psychological interventions with conventional medical treatment seems prudent.[11]

IBD had a considerable impact on work and economic burden in the present study. Many patients, especially young respondents and those with CD, had missed school or work in the 6 months prior to the study, consistent with other reports,[8,27] which, for many patients, is a source of stress and can be the basis for hurtful comments or employment problems. Accordingly, medical discussions should consider work and economic burden as important facets of treatment among Korean patients with IBD.

With regard to building human relationships, IBD can lead to decreased physical intimacy and social activity.[28,29] Being able to talk about IBD-related problems in a supportive group setting was helpful for many respondents, as was the awareness created by health care professionals regarding the influence of IBD on these aspects of life.

This study had several limitations. Firstly, the survey was a self-completed instrument and was only available online, so individuals without Internet access could not participate. Thus, the results cannot be generalized to the entire population. Secondly, the survey questionnaire was not validated. Finally, self-assessment introduces the possibility of recall bias concerning aspects such as medication use and emergency care. Some patients might have overestimated the negative impact of IBD on their lives.

Despite the limitations, our study is meaningful because it is the first large-scale study to investigate the effects on IBD on the daily life of Korean patients. The results would be valuable in devising strategies of care, and campaigns to increase the awareness of IBD in Korea.

In conclusion, IBD considerably affects the daily life of the patients, including their work, school, and social relationships. Treatment that addresses that full spectrum of a patient's life would be more effective.

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Supplementary Material 1. A Survey of Patients with Inflammatory Bowel Disease (IBD)

Demographics

Sex	1. Male 2. Female
Age	① Less than 10 years [<10 years] ② 10~19 years ③ 20~24 years ④ 25~29 years ⑤ 30~34 years ⑥ 35~39 years ⑦ 40~44 years ⑧ 45~49 years ⑨ 50~54 years ⑩ 55~59 years ⑪ 60~64 years ⑫ >65 years
Marital status	① Single ② Married
With or without children	① Have a child (ⓐ one (child) ⓑ two (children) ⓒ three (children) ⓓ four (children) ⓔ Other (children)) ② No children
Occupation	① Student ② Company employee (office job, technical job) ③ Business administrative position ④ Professional freelancer ⑤ Private business ⑥ Sales and service ⑦ Simple labor/technical officer/ production ⑧ Agriculture / Forestry / Fisheries ⑨ Housewife ⑩ Unemployed ⑪ Other ( )
Average monthly income (household)	① <2,000,000 won ② 2,000,000~2,490,000 won ③ 2,500,000~2,990,000 won ④ 3,000,000~3,490,000 won ⑤ 3,500,000~3,990,000 won ⑥ 4,000,000~4,490,000 won ⑦ 4,500,000~4,990,000 won ⑧ 5,000,000~6,990,000 won ⑨ 7,000,000~9,990,000 won ⑩ ≥10,000,000 won
Occupied area	① Seoul ② Metropolitan City (Busan, Gwangju, Daegu, Daejeon, Incheon, Ulsan) ③ City ④ Town ⑤ Other ( )
Society membership status	① The Crohn's Family Lovers Committee ② UC Lovers Committee ③ Other ( ) ④ Not joined

• Which disease of IBD are you diagnosed?
① Corhn's disease (CD)   ② Ulcerative colitis (UC)   ③ Other ( )
• Which is a period of the applicable disease?
① 2 years   ② 2-5 years   ③ 5-10 years   ④ >10 years
• Which is the current treatment drug/therapeutic measures?
① Steroids   ② 5 ASA (asacol( ) pentasa( ) salofalk( ) zopyrin( ))
③ Salazine   ④ Colazal   ⑤ Immunomodulator   ⑥ Biologics   ⑦ Probiotics

Experience with IBD – Disease Diagnosis and Current Status

1. When did you experience the symptoms of IBD first?

   ① 1 year or less   ② 1-3 years ago   ③ 4-5 years ago   ④ 6~7 years ago   ⑤ 7~9 years ago   ⑥ over 10 years ago

2. When did you visit a hospital due to IBD after you experienced first symptom?

   ① within 1 month
   ② 1~3 months
   ③ 3~6 months
   ④ 6 month~1 year
   ⑤ 1 year~2year
   ⑥ 2~5 years
   ⑦ over 5 years

2-1. Why you visited a hospital after a year passed since you have experienced symptom?

   ① Because symptoms were not severe
   ② Did not notice disease
   ③ Have no time
   ④ Could not afford it financially
   ⑤ Have difficulty in visiting a hospital and getting a diagnosis
   ⑥ Did not know which hospital I should visit
   ⑦ Other (   )

3. How long did it take to get final IBD diagnosis through a health care professional since you noticed first symptoms?

   ① < 3 months   ② 3~6 months   ③ 6 months ~ 1 year   ④ 1~2 years   ⑤ 2~5 years   ⑥ ≥ 5 years

4. Have you ever visited the emergency room because of emergency situations caused by IBD before you got diagnosed? If so, how many times did you visit?

   ① Yes (times)   ② No

5. Which is the current status of IBD?

   ① Asymptomatic status   ② Have symptoms, but they are controlled by medicine   ③ Status that symptoms are changed for the better or worse

6. Have you ever hospitalized in the past 5 years? If so, when?

   ① Yes (ⓐ 2013   ⓑ 2012   ⓒ 2011   ⓓ 2010   ⓔ 2009   ⓕ 2008)
   ② No

7. Have you ever experienced a surgery before due to IBD?

   ① Yes (ⓐ one time   ⓑ two times   ⓒ three times   ⓓ four times   ⓔ 5 or more times)
   ② No

8. Do you have any other systemic associated disease besides IBD?

   ① Yes, I have. (ⓐ rheumatoid arthritis   ⓑ ankylosing spondylitis   ⓒ psoriasis)
   ② No, I don't have.

9. Have you ever experience cramps or abdominal pain? How many days you usually experience per one week?

   ① Yes, I have (ⓐ one day   ⓑ two days   ⓒ three days   ⓓ four days   ⓔ five days   ⓕ six days   ⓖ everyday)
   ② No, I haven't

10. Have you had a sudden diarrhea that cannot be tolerated within recent 6 months? How many days you usually experience it?

    ① Yes, I have (ⓐ one day ⓑ two days ⓒ three days ⓓ four days ⓔ five days ⓕ six days ⓖ every day)

    ② No, I don't have

11. How about your status when there are bad symptoms or no symptoms?

		Very often	Often	Sometimes	Rarely	Never
11-1	Felt tired, weak and worn out in daily life during flare up	5	4	3	2	1
11-2	Felt tired, weak and worn out in daily life during remission	5	4	3	2	1
11-3	Felt stressed and affected psychologically during remission	5	4	3	2	1

Treatments

12. Are you meeting health care professionals currently because of IBD? Please choose those you are meeting.

① Yes	① Primary hospitals/ clinics doctor (ⓐ internal medicine ⓑ family physician ⓒ surgery department ⓓ proctological surgery center ⓔ neuropsychiatry department ⓕ pediatric department) ② General hospital specialist (ⓐ gastroenterologist ⓑ anorectal surgeon ⓒ rheumatologist ⓓ psychiatrist) ③ Public health center ④ Oriental medicine clinic ⑤ Psychologist
② No	

13. Have you received steroid medication or are you receiving steroid medication? What do you think about drug effects?

		Yes	No
13-1	Have used steroids for the last 1 year for the relaxation of IBD symptoms	1	2
13-2	Kept using steroids at the time of severe symptoms	1	2

		Very often	Often	Sometimes	Rarely	Never
13-3	Worried about the effects of long-term effects of steroids on my health	5	4	3	2	1
13-4	Experience side effects	5	4	3	2	1

Impacts of IBD on Daily Life – Impact on Relationship

14. Do you think that IBD prevents from keeping relationship maintenance / consolidation with acquaintance or relationship formation with new people?

		Very often	Often	Sometimes	Rarely	Never
14-1	Prevented from making or keeping friends	5	4	3	2	1
14-2	Had an intimate relationship wane or end due to their IBD	5	4	3	2	1
14-3	Felt stress about keeping an intimate family relationship	5	4	3	2	1
14-4	Meeting others with IBD made them more optimistic	5	4	3	2	1
14-5	Patient's association had beneficial impact on their life	5	4	3	2	1

Work Impact

15. Overall work impact of inflammatory bowel disease

		Very often	Often	Sometimes	Rarely	Never
15-1	Cancelled or rescheduled an appointment	5	4	3	2	1
15-2	Left school or office early	5	4	3	2	1
15-3	Absence from school or work	5	4	3	2	1
15-4	Took time off from school or work	5	4	3	2	1
15-5	Felt stress about taking time off work or school	5	4	3	2	1
15-6	Received unfair comments at work or school	5	4	3	2	1
15-7	Suffered discrimination or being ostracized	5	4	3	2	1
15-8	Decline in income or academic ability	5	4	3	2	1
15-9	Unable to perform their full potential	5	4	3	2	1

16. What is the number of days which is absent from school or work or left on vacation within recent 6 months?
    (Total   day(s))

Economic Impact

17. How much money do you spend per one month for the treatment of IBD?
    ① 50 million won or less   ② 50~100 million won   ③ 100~200 million won   ④ 200 million or more

18. To what extent is IBD likely to affect your finance?

		Very often	Often	Sometimes	Rarely	Never
18-1	Stopped medical treatment due to economic burden	5	4	3	2	1
18-2	Felt sorry for my family bearing treatment cost	5	4	3	2	1
18-3	The quality of life had decreased due to economic burden.	5	4	3	2	1
18-4	Having felt like committing suicide	5	4	3	2	1
18-5	Having felt anxiety about the future	5	4	3	2	1

Pregnancy

19. To what extent is IBD likely to affect your pregnancy, childbirth, and parenting?

*Please indicate your experience or thoughts about pregnancy and childbirth.		Very often	Often	Sometimes	Rarely	Never
19-1	Did not want marry (because of having guilty of spouse)	5	4	3	2	1
19-2	Did not want to get pregnant	5	4	3	2	1
19-3	Did not want to get pregnant with a fear of harming babies. (Miscarriage, fetal deformities, and premature birth, etc.)	5	4	3	2	1
19-4	Did not want to get pregnant with a fear that my disease might be aggravated	5	4	3	2	1
19-5	I am afraid that my disease is passed down to my children.	5	4	3	2	1
19-6	Stopped medication for breastfeeding (I think I should stop it.)	5	4	3	2	1
19-7	My child is healthy.	5	4	3	2	1
19-8	Had to stop all drugs during pregnancy (I think taking therapeutic medicines should be stopped during pregnancy.)	5	4	3	2	1
19-9	Stopped breast feeding (I thought that I should stop it)	5	4	3	2	1

Expectation / Requirement for Disease Diagnosis / Treatment Environment

20. Which is the most expectation from IBD treatment / management? Please pick up the most three important things in the ranking order.

1st place (   ), 2nd place (   ), 3rd place (   )
① Treatment with few side effects
② Treatment for the fast relief of symptom
③ Treatment with less time charge such as visit to hospital etc.
④ Treatment with less economic burden
⑤ Treatment that is effective in associated disease prevention / treatment
⑥ Other (   )

21. What do you think about the treatment / management environment improvement / development of the inflammatory bowel disease (IBD)?

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
21-1	Hope that the government support for IBD treatment expenses will be expanded	5	4	3	2	1
21-2	Hope that the government support for IBD diagnosis expenses will be expanded	5	4	3	2	1
21-3	Hope that the government support for IBD-related auxiliary treatment (such as probiotics etc.) will be expanded	5	4	3	2	1
21-4	Hope that efforts will be made to alleviate prejudice and misconceptions against IBD patients and increase related awareness	5	4	3	2	1

Disease-related Information Acquisition

22. Please tell us how to get information about inflammatory bowel disease (IBD) in the ranking order.

1st place (   ), 2nd place(   ), 3rd place (   )
① Doctor / Heath care professional
② Patient group
③ Acquaintance
④ TV broadcasting
⑤ Radio broadcasting
⑥ Newspaper
⑦ Magazine
⑧ Website (Government / Society operation)
⑨ Internet search engine
⑩ Promotions such as hospital / pharmaceutical brochure
⑪ Other (   )

23. Tell us what you want to know inflammatory bowel disease (IBD) specifically.

(   )