

See “Impact of inflammatory bowel disease on daily life: an online survey by the Korean Association for the Study of Intestinal Diseases” on page 338.

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

Demographics	
Sex	1. Male 2. Female
Age	<ul style="list-style-type: none"> 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 (a) one (child) b) two (children) c) three (children) d) four (children) e) Other (children)) ② No children
Occupation	<ul style="list-style-type: none"> 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)	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> ① Seoul ② Metropolitan City (Busan, Gwangju, Daegu, Daejeon, Incheon, Ulsan) ③ City ④ Town ⑤ Other ()
Society membership status	<ul style="list-style-type: none"> ① The Crohn's Family Lovers Committee ② UC Lovers Committee ③ Other () ④ Not joined

- Which disease of IBD are you diagnosed?
① Crohn'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

- 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
- 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 ()
- 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
- 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
- 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
- Have you ever hospitalized in the past 5 years? If so, when?
① Yes (a) 2013 (b) 2012 (c) 2011 (d) 2010 (e) 2009 (f) 2008
② No
- Have you ever experienced a surgery before due to IBD?
① Yes (a) one time (b) two times (c) three times (d) four times (e) 5 or more times
② No
- Do you have any other systemic associated disease besides IBD?
① Yes, I have. (a) rheumatoid arthritis (b) ankylosing spondylitis (c) psoriasis
② No, I don't have.
- Have you ever experience cramps or abdominal pain? How many days you usually experience per one week?
① Yes, I have (a) one day (b) two days (c) three days (d) four days (e) five days (f) six days (g) 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 (a one day b two days c three days d four days e five days f six days g 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 (a internal medicine b family physician c surgery department d proctological surgery center e neuropsychiatry department f pediatric department)
 - ② General hospital specialist (a gastroenterologist b anorectal surgeon c rheumatologist d 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 / Health 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.

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