Physicians Should Provide Shared Decision-Making for Anti-TNF Therapy to Inflammatory Bowel Disease Patients

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Shared decision-making may increase the effectiveness of inflammatory bowel disease (IBD) treatment, as different anti-tumor necrosis factor (anti-TNF) administrations may have different effects on the quality of life (QOL). Patient preference is integral to the selection of anti-TNFs and their routes of administration, however, previous studies on the patient preference to anti-TNFs are inconsistent and limited. We evaluated the predictive factors for preferences to anti-TNF administrations in IBD patients between March and August in 2015. Consecutive adult IBD patients who received care at one of four university hospitals in Korea were invited to participate in this study. Patients were administered questionnaires about their preferences regarding anti-TNF therapy and QOL. During the study period, 322 IBD patients completed the questionnaires. IBD patients preferred intravenous anti-TNFs to subcutaneous anti-TNFs (2.4:1), and 58.4% of patients preferred shared decision-making. When comparing subcutaneous anti-TNF therapy with intravenous anti-TNF therapy, patients with higher income levels, patients who experienced adverse events with prior medication and patients with a longer disease duration preferred subcutaneous anti-TNF therapy over intravenous anti-TNF therapy ($P = 0.043$, $P = 0.000$, and $P = 0.029$, respectively). In a logistic regression analysis, high income level (odds ratio [OR] 2.0; 95% confidence interval [CI] 1.1–3.5; $P = 0.026$) and an adverse event with prior medication (OR 4.0; 95% CI 2.2–7.2; $P = 0.000$) and were found to be independent predictors for preference to subcutaneous anti-TNF therapy. Therefore, physicians should share decision-making with their IBD patients regarding the mode of anti-TNF administration.

Keywords: Inflammatory Bowel Disease; Crohn's Disease; Ulcerative Colitis; Shared Decision-Making; Anti-TNF

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic, disabling disorder of the gastrointestinal tract. In the treatment of IBD, anti-tumor necrosis factor (anti-TNF) therapy significantly increased remission rates of IBD (1-6). Anti-TNF therapies have similar efficacy and safety profiles, however, they differ in modes of administration and dosing schedules. Intravenous anti-TNFs, such as infliximab, are usually administered once every eight weeks by a trained healthcare professional (1,2,5,6). For intravenous anti-TNFs, patients are required to attend clinics for administration and clinical observation, but the patient and/or family members have minimal responsibilities for the administration of the drug. Subcutaneous anti-TNFs, such as adalimumab, are usually administered once every two weeks (3-6). For subcutaneous anti-TNFs, patients are not required to attend clinics at specific times, allowing flexibility in hospital visits. However, patients are required to be responsible for the administration of the drug. In this regard, physicians should discuss with their IBD patients about the anti-TNF options.

Shared decision-making should be considered when different treatment options may have different effects on the quality of life (QOL) of patients (7,8), as it can increase the effectiveness of treatment. In this regard, different modes and schedules of anti-TNF therapies may offer potential opportunities for shared decision-making to IBD patients (5,6). Peake et al. (9) reported that subcutaneous anti-TNFs were preferred over intravenous anti-TNFs in 36 Crohn's disease (CD) patients, but Allen et al. (10) reported the contrary preference in 78 IBD patients. Both studies were limited as they were inconsistent and based on a single center with a small number of patients (9,10). Recently, Kim et al. (11) reported the intravenous anti-TNF therapies were preferred over subcutaneous anti-TNFs in 189 CD patients. Patient and physician preferences for anti-TNFs may be different between Western and Asian countries, as many factors, such as lack of insurance reimbursement, high medical costs, concerns about tuberculosis infection and cultural background, may have different influence on the preference to anti-TNFs in Asian patients (9-13). Furthermore, Asian patients may have a different preference for being involved in shared decision-making, as it

may be influenced by demographic factors, knowledge about IBD, their experience and relationship with healthcare professionals (14). Preference studies for anti-TNF therapies in Asian IBD patients should be warranted, considering the increasing prevalence of IBD in Asian countries (15-18).

The aim of this study was to evaluate the predictive factors for preferences to anti-TNF therapies and shared decision making for IBD patients in Korea.

MATERIALS AND METHODS

Patients

Between March and August in 2015, consecutive adult IBD patients, who received care for at least 6 months regardless of anti-TNF therapies, were invited to participate in this study at four university hospitals in Korea. IBD patients were interviewed by the study coordinators to collect information on the following variables: age, sex, tobacco/alcohol use, duration of IBD, marital status, employment status, education level, income level, medical treatment, and prior hospitalizations or surgeries. Demographic, clinical, and disease-related characteristics of IBD patients were compared according to their preferences of anti-TNF therapy. Patients were administered two questionnaires: 'Patient preferences to anti-TNF therapy' (Appendix 1 and 2) (9,10) and 'Crohn's and ulcerative colitis questionnaire-8 (CUCQ-8)' (Appendix 3 and 4) (19). Subjects were excluded if they were unable to comprehend the questionnaire or had an active psychiatric disorder.

Development of anti-TNF information sheet

A drug information sheet was provided to accompany the questionnaires mentioned above. The information sheet provides patients with reliable, accurate, and unbiased information to help them choose an appropriate anti-TNF therapy based on information provided by the Crohn's and Colitis Foundation of America (http://www.ccfa.org/resources/biologic-therapies.html). It was designed to enable patients to answer the study questionnaire as accurately and reliably as possible. The key topics in the drug information leaflet were: 1) indications of anti-TNFs for IBD; 2) summaries of the intravenous and subcutaneous anti-TNFs; and 3) key differences between the two anti-TNFs, especially in terms of their mode and schedule of administration. The quality of the information presented about the anti-TNFs was assessed using a validated tool that is used by health professionals and consumers to judge the quality of written health information (20). The information sheet and questionnaire were confirmed as reliable and valid by four health professionals who were not involved in this study. The questionnaire's readability was tested using the Korean reading scale by researchers and patients not involved in the current study before starting the study. To establish whether patients would be

able to understand the information sheet and questions, ten volunteers (hospital visitors and relatives of the patients) were randomly selected to check a pilot questionnaire and information sheet. In response to their comments, slight changes were made to the wording.

The questionnaires for preferences and QOL

The 'Patient preferences for anti-TNF therapy' questionnaire was designed to pose specific questions about the patient's anti-TNF therapy, their preference for intravenous or subcutaneous anti-TNFs, and the reasons for these preferences. Patients were asked, in a hypothetical scenario, which anti-TNF administration they would prefer if given the choice in the future. It followed a predominantly closed-ended question format. The questionnaire asked patients about: 1) the influence of IBD on their lifestyle or employment; 2) preferences for anti-TNFs in terms of their mode and schedule of administration; and 3) shared decision-making. For the choice of anti-TNF therapy, the possible responses were: 1) Group A = preference for intravenous anti-TNFs at the hospital every 8 weeks; 2) Group B = preference for subcutaneous anti-TNFs at home every 2 weeks; or 3) Group C = no preference for any anti-TNF therapy. The patients were asked for the reasons for their choices. In addition, patients who had previously been administered any anti-TNFs were asked whether they would choose the same or an alternative route of administration in the future, if indicated.

CUCQ-8 is a short, valid, reliable tool to measure QOL in all IBD patients (19). The CUCQ-8 questionnaire includes questions about a patient's bowel problem and how these problems have affected their life over the last two weeks. The CUCQ-8 assesses subjective feelings of tiredness, being unwell, or upset, the presence of abdominal pain or bloating, the need to rush to the toilet or get up at night to use the toilet, and being prevented from going out socially due to a bowel condition. As validity, internal reliability, reproducibility, and responsiveness of CUCQ-8 were confirmed in IBD patients (19), disease-related QOL was measured with CUCQ-8 in this study.

Statistical analysis

Continuous variables are expressed as the mean ± standard deviation (SD) or median (range), and categorical variables are presented as the number of patients and percentage. Demographic and clinical variables in the three groups were compared using analysis of variance for continuous variables and a χ^2 test for categorical variables. A multivariate logistic regression analysis was used to determine independent predictors of a preference to mode of anti-TNF administration. Odds ratios (ORs) with 95% confidence intervals (CIs) were calculated with adjustments for all of the relevant variables with significant univariate differences between groups ($P < 0.05$). Two-tailed P values < 0.05 were considered statistically significant. Statistical

analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 18.0 for Windows (SPSS Inc., Chicago, IL, USA).

Ethics statement

This study was approved by the Institutional Review Board of Kyung Hee University Hospital at Gangdong (IRB KHNMC-2015-03-008). However, informed consent from the IBD patients was waived for this survey-based study.

RESULTS

During the study period, 322 patients completed the questionnaires. IBD patients included 217 (67.4%) men and 105 (32.6%) women, and 148 (46.0%) CD and 174 (64.0%) ulcerative colitis. Their mean age was 39.7 ± 14.2 years, and mean duration of IBD was 5.9 ± 5.2 years.

Table 1 shows the preferences to anti-TNF therapies in IBD patients. IBD patients preferred intravenous over subcutaneous anti-TNF therapies with a 2.4:1 ratio. The main reason given for a preference to intravenous anti-TNF was 'I don't like the idea of self-injecting' (73.4%), and the main reason given for subcutaneous anti-TNF was 'the convenience of injecting at home' (73.1%). In this study, 58.4% of patients preferred shared decision-making. Approximately 2/3 (63.1%) of patients who had previously or currently receiving anti-TNFs reported that they wanted to change to the alternative anti-TNF regimens, if given the choice in the future.

Table 1. Preferences for anti-TNF therapy in patients with IBD

Preferences in choosing anti-TNF therapy	Patients (n = 322)
Preferences to anti-TNF therapy, No. (%)	
Group A:Group B	188 (58.4):78 (24.2)
Group C	56 (17.4)
Reasons of preference route cited, No. (%)	
Group A*: (1) "I don't like the idea of self-injecting"	138 (73.4)
(2) "I prefer to take the medication less often"	13 (6.9)
(3) "I prefer the regular contact with doctor"	3 (1.6)
Group B†: (1) "I prefer the convenience of injecting at home"	57 (73.1)
(2) "No requirement to visit hospitals regularly"	6 (7.7)
(3) "I prefer the less complicated technique of drug administration"	0 (0.0)
Preferences for decision-making in choosing anti-TNF therapy, No. (%)	
(1) Decision made by both the doctor and patient together	188 (58.4)
(2) Decision made by the doctor alone	77 (23.9)
(3) Decision made by the patient alone	57 (17.7)
Change to alternative anti-TNF therapy if given the choice in the future for the patients who had previously or are currently receiving anti-TNFs, No. (%)	99/157 (63.1)

Group A means 'preference for intravenous anti-TNF at the hospital every 8 weeks,' Group B means 'preference for subcutaneous anti-TNF at home every 2 weeks,' and Group C means 'no preference for any biological therapy.'
TNF = tumor necrosis factor, IBD = inflammatory bowel disease.
*Thirty-four cases in group A; and †15 cases in group B did not answer this survey item.

Table 2. Demographic and clinical characteristics of patients with IBD in relation to their preferences for anti-TNF therapy

Parameters	Group A (n = 188)	Group B (n = 78)	Group C (n = 56)	P value
Disease type				0.544
CD, No. (%)	89 (47.3)	37 (47.4)	22 (39.3)	
UC, No. (%)	99 (52.7)	41 (52.6)	34 (60.7)	
Age, yr*	38.5 (18.0–80.0)	35.5 (16.0–74.0)	42.5 (18.0–81.0)	0.128
Age at IBD diagnosis, yr*	31.5 (12.0–74.0)	29.0 (13.0–65.0)	34.0 (13.0–70.0)	0.144
Sex (male), No. (%)	128 (68.1)	53 (68.0)	36 (64.3)	0.297
Body mass index, kg/m²*	22.3 (16.2–35.2)	22.3 (15.7–31.7)	22.0 (17.3–28.4)	0.562
Current smoker, No. (%)	34 (18.1)	11 (14.1)	5 (8.9)	0.318
Alcohol use, No. (%)	39 (20.7)	18 (23.1)	12 (21.4)	0.915
Marital status (married), No. (%)	106 (56.4)	35 (44.9)	31 (55.4)	0.219
Religious (yes), No. (%)	70 (37.2)	31 (39.7)	21 (37.5)	0.927
Employed (yes), No. (%)	23 (48.9)	15 (48.4)	7 (53.8)	0.810
Education (≥ university), No, (%)	118 (62.8)	56 (71.8)	29 (51.8)	0.060
Travel time to hospital (≥ 1 hr), No. (%)	37 (19.7)	18 (23.1)	17 (30.4)	0.239
Income/mon (≥ 4,305 dollar†), No. (%)	51 (27.1)	31 (39.7)	12 (21.4)	0.045

Group A means 'preference for intravenous anti-TNF at the hospital every 8 weeks,' Group B means 'preference for subcutaneous anti-TNF at home every 2 weeks,' and Group C means 'no preference for any biological therapy.'
IBD = inflammatory bowel disease, TNF = tumor necrosis factor, CD = Crohn's disease, UC = ulcerative colitis.
*Continuous variables were expressed as median (range); †Exchange rate is quoted at 1,161 won to the dollar as of October 8, 2015.

Table 3. Disease-related characteristics of patients with IBD in relation to their preferences for anti-TNF therapy

Parameters	Group A (n = 188)	Group B (n = 78)	Group C (n = 56)	P value
Prior medication history, No. (%)				
Prior use of steroids	118 (62.8)	54 (69.2)	31 (55.4)	0.258
Prior use of immunomodulators	118 (62.8)	48 (61.5)	25 (44.6)	0.048
Prior use of anti-TNFs	75 (39.9)	26 (33.3)	12 (21.4)	0.037
Adverse events with prior medication	33 (17.6)	36 (46.2)	13 (23.2)	0.000
Hospitalization for IBD, No. (%)	131 (69.7)	47 (60.3)	29 (51.8)	0.034
Prior surgery for IBD, No. (%)	45 (23.9)	12 (15.4)	10 (17.9)	0.246
Disease duration, yr	5.2 ± 4.7	6.7 ± 5.3	6.9 ± 6.4	0.029
Clinic visits (days/year)	5.8 ± 3.1	5.6 ± 2.9	5.1 ± 2.3	0.378
Hospital stay (days/year)	3.7 ± 9.1	2.8 ± 8.3	1.6 ± 3.7	0.223
Compliance to treatment (yes), No. (%)	124 (66.0)	49 (62.8)	41 (73.2)	0.442
Influence of IBD, No. (%)				
Lifestyle (≥ moderate)	68 (36.2)	26 (33.3)	10 (17.9)	0.036
Employment (≥ moderate)	54 (28.7)	27 (34.6)	10 (17.9)	0.093
QOL (measured with CUCQ-8)				
Days felt tired	5.3 ± 4.6	4.2 ± 4.1	4.3 ± 4.4	0.085
Prevented from going out socially by bowel condition (not at all), No. (%)	93 (49.5)	41 (52.6)	32 (57.2)	0.613
Days felt generally unwell	3.2 ± 3.9	3.1 ± 4.1	3.2 ± 4.8	0.978
Days felt pain in abdomen	1.8 ± 3.0	1.3 ± 2.3	1.5 ± 3.2	0.432
Nights getting up to use a toilet	1.5 ± 3.4	1.1 ± 2.6	1.1 ± 2.4	0.408
Days felt bloated	2.6 ± 3.9	2.5 ± 3.9	2.0 ± 3.4	0.577
Feeing upset (not at all), No. (%)	69 (36.7)	28 (35.9)	20 (35.7)	0.312
Days had to rush to the toilet	2.1 ± 3.1	2.1 ± 3.3	2.3 ± 4.4	0.919

Values are presented as mean ± standard deviation (SD) or number (%). Group A means 'preference for intravenous anti-TNF at the hospital every 8 weeks,' Group B means 'preference for subcutaneous anti-TNF at home every 2 weeks,' and Group C means 'no preference for any biological therapy.'
IBD = inflammatory bowel disease, TNF = tumor necrosis factor, SD = standard deviation, QOL = quality of life, CUCQ-8 = Crohn's and ulcerative colitis questionnaire-8.

Table 4. Multivariate logistic regression analysis of predictors for subcutaneous anti-TNF therapy over intravenous anti-TNF therapy

Variables	OR (95% CI)	P value
Monthly income (< 4,305 vs. ≥ 4,305 dollar)	1.959 (1.068–3.536)	0.026
Adverse event with prior medication (no vs. yes)	3.983 (2.197–7.222)	0.000
Duration of IBD, mon (continuous)	1.053 (0.996–1.114)	0.069

TNF = tumor necrosis factor, OR = odds ratio, CI = confidence interval IBD = inflammatory bowel disease.

Demographic, clinical, and disease-related characteristics of IBD patients were compared according to the patients' preference to anti-TNF therapies. Demographic and clinical characteristics of IBD patients was similar, however, higher income level was significantly different between three groups (Table 2). Disease-related characteristics of IBD patients were also compared between three groups (Table 3). Disease-related characteristics was also similar different between three groups, except for prior use of immunomodulators or anti-TNFs, adverse events with prior medication, hospitalizations for IBD, disease duration and much (≥ moderate) influence of IBD on their life style. In general, QOL, as measured by the CUCQ-8, was similar between three groups.

In a subgroup analysis comparing group A and B after excluding group C, patients with higher income levels, patients who experienced adverse events with prior medication and patients with a longer disease duration preferred subcutaneous anti-TNF

therapy ($P = 0.043$, $P = 0.000$, and $P = 0.029$, respectively). To determine predictors for preference to subcutaneous over intravenous anti-TNF therapy, we performed a logistic regression analysis adjusted for income level, adverse events with prior medication and disease duration, which showed univariate differences between group A and B. In this analysis, high income level (OR 2.0; 95% CI 1.1–3.5; $P = 0.026$) and an adverse event with prior medication (OR 4.0; 95% CI 2.2–7.2; $P = 0.000$) were found to be independent predictors for preference to subcutaneous anti-TNF therapy (Table 4).

DISCUSSION

This is the largest study on the preferences to anti-TNF therapy in Asian IBD patients. In the present study, intravenous anti-TNF was preferred over subcutaneous anti-TNF with a 2.4:1 ratio in IBD patients. Korean IBD patients might be more familiar with intravenous anti-TNF than subcutaneous anti-TNF, as intravenous anti-TNF was approved five years earlier than subcutaneous anti-TNF in 2005. The main reason given for the preference for intravenous anti-TNF was 'I don't like the idea of self-injecting' (73.4%), and the main reason given for subcutaneous anti-TNF was 'the convenience of injecting at home' (73.1%), which were consistent with previous studies (9,10). In the United Kingdom, intravenous anti-TNF was preferred over subcutaneous anti-TNFs (1.7:1) in 78 IBD patients (10). However, an-

other study reported that subcutaneous anti-TNF was preferred over intravenous anti-TNFs (1.8:1) in 36 CD patients (9). A recent Korean study reported that intravenous anti-TNF was preferred over subcutaneous anti-TNF (1.7:1) in 189 anti-TNF naïve CD patients (11). Results of previous Western studies were not consistent and limited due to the small number of patients from a single center (9,10). The Korean study was also limited as it included only anti-TNF naïve CD patients (11). Except for IBD, patient preference for anti-TNF therapy have only been reported in patients with rheumatoid arthritis. Rheumatoid arthritis patients predominantly preferred subcutaneous over intravenous administrations (21,22), as they had a limited mobility due to rheumatoid arthritis. However, IBD patients may be little influenced by disease characteristics on their preference for anti-TNF therapy.

In this study, approximately 58% of patients preferred shared decision-making. In a survey of 1,056 IBD patients in Germany, 67% of patients preferred shared decision-making (23). In a survey of 1,067 patients in the Netherlands, most (81%) patients reported that shared decision-making was a 'very important' process (24). Recently, Siegel et al. (25,26) reported interesting survey results for shared decision-making from both patients' and gastroenterologists' perspectives. From gastroenterologists' perspective, only 12% of 106 gastroenterologists had a systemic documented approach for the shared decision-making process (25). From the patients' perspective, however, over 2/3 of 355 IBD patients reported much satisfaction from shared decision-making (26). In the present study, approximately 2/3 of patients who had previously received or were currently receiving anti-TNFs wanted to change to alternative anti-TNF therapies. Therefore, physicians should provide the shared decision-making process for their IBD patients, especially in choosing anti-TNF therapies. Lower preference rate for the shared decision-making in our study than those from Western studies (23,24,26) might be explained by differences in health care experience, health status, decision and information preferences, and socio-demographic variables (14).

Little is known about the potential predictors for preference to anti-TNF therapy in IBD patients. In the present study, high income level (OR 2.0; 95% CI 1.1–3.5; $P = 0.026$) and adverse event with prior medication (OR 4.0; 95% CI 1.2–7.2; $P = 0.000$) were found to be independent predictors for preference to subcutaneous anti-TNF therapy. This makes sense, as subcutaneous anti-TNF therapy may be attractive to patients who are more active or in the workforce (21). Subcutaneous administration may offer patients more flexibility and convenience without need for medical appointments during business hours (27). Furthermore, subcutaneous anti-TNF therapy may be attractive to patients who experienced an adverse event with prior medication as they desire newly-developed medications. Therefore, physicians should discuss the use of anti-TNF therapy with their IBD

patients considering these factors. Subcutaneous administration decreased the need for hospital visits, however, travel time to the hospital was not a predictive factor for subcutaneous preference in our study. In another study (11), however, the travel time to hospital was a predictive factor for subcutaneous preference.

The present study had several limitations. First, our study was based on IBD patients from large, tertiary referral centers, which limits the ability to generalize our findings. Our patients may have had a more complicated disease course and therefore referred to our centers. It is possible that, in a general gastroenterology community practice, with patients who perhaps have more mild cases of IBD, patients may have different preferences to anti-TNF therapy. However, anti-TNF therapy is often used for IBD patients with a more complicated disease course in large centers of Korea (28). Second, we recognize that there may be geographic and economic aspects that impact on anti-TNF therapy, which can also limit the generalizability of our findings. Therefore, the preference for anti-TNFs should be reevaluated in different countries, especially in other Asian countries. The final limitation is that our study relied on a hypothetical scenario about the choice of anti-TNF therapies, and respondents may not make the same decision in a real clinical setting.

In conclusion, high income levels and an adverse event with prior medication were independent predictors for preference to subcutaneous anti-TNF therapy. Therefore, physicians should provide shared decision-making to their IBD patients for the mode of anti-TNF administration. Further studies on the preferences to anti-TNF therapy should be reevaluated in IBD patients from other Asian countries.

DISCLOSURE

AUTHOR CONTRIBUTION

Study design: Cha JM, Yang SK. Data analysis and interpretation: Park DI, Park SH, Shin JE, Kim WS. Writing, review, and revision of manuscript: Cha JM. Approval of final manuscript: all authors.

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Appendix 1. Preferences of anti-TNFs in patients with inflammatory bowel disease.

The following questions ask for your views about your bowel problem and how it has affected your life over the last two weeks. Please answer all the questions. If you are un-sure about how to answer any question, just give the best answer you can. Do not spend too much time answering, as your first thoughts are likely to be the most accurate. If you do not wish to answer any of these questions, please leave it blank and complete the details of the question and reason(s) why it was not answered.

Lifestyle & employment

Q1. How much has your life-style been affected by IBD?
    1) Not at all   2) A mild influence   3) A moderate influence   4) A severe influence   5) An extreme influence

Q2. How much influence has IBD had on your employment?
    1) Not at all   2) A mild influence   3) A moderate influence   4) A severe influence   5) An extreme influence

Q3. How long it will take from your house to your hospital?
    1) Less than 30 minutes   2) 30 minutes–1 hour   3) 1–2 hours   4) more than 2 hours

This question is about a hypothetical scenario as to which route of administration of anti-TNF therapy you might choose in the future.

Preference of anti-TNFs

Q4. Which mode of anti-TNF administration would you prefer if you have the choice in the future?
    1) Intravenous administration of anti-TNFs in the hospital every 8 weeks
    2) Subcutaneous administration of anti-TNFs at home every 2 weeks
    3) No preference for anti-TNF therapy

Q5. Why did you choose the answer 1) or 2) for previous question?
  I chose answer 1), as I …
    1) I do not like the idea of self-injecting.
    2) I prefer to take the medication less often.
    3) I prefer the regular contact with health professionals.
  I chose answer 2), as I …
    1) I prefer the convenience of injecting at home.
    2) I don't have to visit hospitals regularly.
    3) I prefer the less complicated technique of drug administration (no discomfort obtaining intravenous access).
    *Please, skip this question if you answered 3) for previous question.

Q6. How do you want to make decisions regarding the choice of anti-TNF in the future?
    1) I prefer decisions to be made by both the doctor and patient together.
    2) I prefer the doctor alone to make decision.
    3) I prefer making my decisions without clinician input.

This question is only for current or prior anti-TNF user (Q7 & Q8).

Q7. Would you prefer other anti-TNFs if given the choice in the future?   1) No   2) Yes

Q8. Did a doctor's recommendation influence on your choice of anti-TNFs?   1) No   2) Yes

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Appendix 2. Korean version of questionnaire for "Preferences of anti-TNFs in patients with inflammatory bowel disease"

질문에 대해 처음 떠오르는 생각이 가장 정확한 경우가 많기 때문에, 설문에 대한 답변에 많은 시간을 할애하지 마시기 바랍니다. 정확한 답변이 아니라도 가장 가까운 답변을 하시면 됩니다. 질문에 대해 답변이 곤란한 내용이 있다면 답변을 비워두고 다음 질문으로 이동하셔도 되지만, 가급적 모두 답변을 부탁 드립니다.

생활 습관과 환경(질문 1–3)

1. 염증성장질환이 생활 패턴에 얼마나 영향을 주고 있습니까?
   (1) 전혀 영향을 주지 않는다.   (2) 약간 영향을 준다.   (3) 상당히 영향을 준다.   (4) 심하게 영향을 준다.   (5) 엄청난 영향을 준다.

2. 염증성장질환이 직업에 얼마나 영향을 주고 있습니까?
   (1) 전혀 영향을 주지 않는다.   (2) 약간 영향을 준다.   (3) 상당히 영향을 준다.   (4) 심하게 영향을 준다.   (5) 엄청난 영향을 준다.

3. 집에서 병원까지 이동에 걸리는 시간은 얼마나 됩니까?
   (1) 30분 미만   (2) 30분–1시간   (3) 1–2시간   (4) 2시간 이상

다음 질문은 미래에 항TNF 약물을 선택하게 될 때 어떤 투여 경로를 선택할 지에 대한 가상 시나리오에 대한 질문입니다.

항 TNF 약물의 선호도(질문 4–6)

4. 생물학적 제재를 사용하게 된다면 어떤 약물을 선택하시겠습니까?
   (1) 매 8주마다 병원에서 Infliximab 정맥 주사
   (2) 매 2주마다 집에서 Adalimumab 피하 주사
   (3) 아무 주사나 상관 없다(선호도 없음)

5. 위 질문에 대한 답변을 선택한 이유를 골라주세요.
   (1) 번을 선택한 경우 : (1) 자가 주사를 좋아하지 않기 때문에
                          (2) 약물 투여를 더 자주하지 않아도 되기 때문에
                          (3) 병원에 규칙적으로 내원하는 것이 더 좋기 때문에
   (2) 번을 선택한 경우 : (1) 집에서 자가 주사하는 편의성 때문에
                          (2) 정기적으로 병원에 내원하지 않아도 되기 때문에
                          (3) 약물 투여가 덜 복잡하기 때문에
   (3) 번을 선택하셨으면, 답하지 않으셔도 좋습니다.

6. 생물학적 제재의 선택에 대해 의사 결정을 어떻게 하기를 원하십니까?
   (1) 담당 의사와 환자가 같이 상의하여 의사 결정하기를 원한다.
   (2) 담당 의사가 알아서 결정해 주기를 원한다.
   (3) 담당 의사의 조언 없이, 환자 혼자서 결정하기를 원한다.

7–8 문항은 <u>현재 생물학적 제재를 사용 중이거나 과거 생물학적 제재를 사용했던 적이 있는 환자</u>분들만 답변해 주시기 바랍니다.

7. 향후 선택권이 주어진다면, 다른 종류의 생물학적 제재를 사용해 보고 싶습니까?
   (1) 예   (2) 아니오

8. 의사의 충고가 환자 분의 생물학적 제제 선택에 영향을 주었습니까?
   (1) 전혀 영향을 주지 않았다   (2) 약간 영향을 주었다   (3) 상당히 영향을 주었다   (4) 심하게 영향을 주었다   (5) 의사가 결정하였다

Appendix 3. Crohn's and ulcerative colitisquestionnaire-8 (CUCQ-8).

The following questions ask for your views about your bowel problem and how it has affected your life over the last two weeks. Please answer all the questions. If you are unsure about how to answer any question, just give the best answer you can. Do not spend too much time answering, as your first thoughts are likely to be the most accurate. If you do not wish to answer any of these questions, please leave it blank and complete the details of the question and reason(s) why it was not answered.

Q1. On how many days over the last two weeks have you felt tired? ___ days

Q2. In the last two weeks did your bowel condition prevent you from going out socially?

    a) No, not at all, b) Yes, some of the time, c) Yes, most of the time, d) Yes, all of the time

Q3. On how many days over the last two weeks have you felt generally unwell? ___ days

Q4. On how many days over the last two weeks have you felt pain in your abdomen? ___ days

Q5. On how many nights in the last two weeks have you had to get up to use the toilet because of your bowel condition after you have gone to bed? ___ nights

Q6. On how many days over the last two weeks has your abdomen felt bloated? ___ days

Q7. In the last two weeks have you felt upset?

    a) No, not at all, b) Yes, some of the time, c) Yes, most of the time, d) Yes, all of the time

Q8. On how many days over the last two weeks have you had to rush to the toilet? ___ days

Appendix 4. Korean version of Crohn's and ulcerative colitisquestionnaire-8 (CUCQ-8).

다음 질문은 지난 2주동안 장 문제에 대한 귀하의 의견과 장 문제가 어떻게 일상 생활에 영향을 미쳤는지에 대한 질문입니다. 정확한 답변이 아니라도 가장 가까운 답변을 하시면 됩니다. 질문에 대해 처음 떠오르는 생각이 가장 정확한 경우가 많기 때문에, 설문에 대한 답변에 많은 시간을 할애하지 마시기 바랍니다. 정확한 답변이 아니라도 가장 가까운 답변을 하시면 됩니다. 질문에 대해 답변이 곤란한 내용이 있다면 답변을 비워두고 다음 질문으로 이동하셔도 되지만, 가급적 모두 답변을 부탁 드립니다.

1. 지난 2주 동안, 며칠 정도 피로감을 느끼셨습니까? (   )일

2. 지난 2주 동안, 외출하여 사회생활을 하는데 장 문제로 방해받은 적이 있었습니까?
  (1) 전혀 없었다   (2) 약간 있었다   (3) 자주 있었다   (4) 항상 그랬다

3. 지난 2주 동안, 며칠 정도 전반적으로 건강하지 못하다고 느끼셨습니까? (   )일

4. 지난 2주 동안, 며칠 정도 복통을 경험하셨습니까? (   )일

5. 지난 2주 동안, 잠자리에 들었다가 장 문제로 화장실에 가기 위해 일어나야만 했던 날은 며칠이나 되셨습니까? (   )일

6. 지난 2주 동안, 며칠 정도 복부 팽만감(거북함)을 경험하셨습니까? (   )일

7. 지난 2주 동안, 속상한 적이 있으셨습니까?
  (1) 전혀 없었다   (2) 약간 있었다   (3) 자주 있었다   (4) 항상(매일) 속상했다

8. 지난 2주 동안, 며칠 정도 화장실이 급해서 달려간 경험을 하셨습니까? (   )일