

ORIGINAL ARTICLE

염증성 장질환 환자의 치료에 대한 주관적인 필요와 생각: Q 방법론 적용

박용은, 이진, 박종하, 최준혁, 허내운, 박승하, 이윤경¹, 김태오

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Subjective Needs and Thoughts for the Treatment of Patients with Inflammatory Bowel Disease: Applying Q Methodology

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Background/Aims: Inflammatory bowel disease (IBD), including Crohn's disease and ulcerative colitis, is a chronic inflammatory disorder of the gastrointestinal tract that requires lifetime management. Many studies have attempted to establish questionnaires and/or parameters to assess the quality of care for IBD patients. However, no study to date has investigated patients using the Q-methodology, which is subjective and has been studied systematically, to identify and categorize their opinions and subjective thinking about their disease and treatment. We have therefore aimed here to conduct a preliminary study of the Q-methodology to investigate the subjective thinking of IBD patients in Korea.

Methods: Q-methodology, a method of analyzing the subjectivity of questionnaire items, was examined in this study. Inputs from 50 IBD patients were classified into 34 normalized statements using a 9-point scale with a normal distribution. The collected data were analyzed using the QUANL PC program.

Results: Using the Q-methodology, IBD patients were classified into type I, II, III, and IV treatment needs: medical staff-dependent, relationship-oriented, information-driven, and social awareness, respectively.

Conclusions: The subjective needs of IBD patients and their thoughts about the treatment can be classified into four types. Our findings suggest that we can establish a systematic strategy for personalized care according to patient type. (Korean J Gastroenterol 2021;78: 37-47)

Key Words: Inflammatory bowel diseases; Q methodology; Quality of health care

INTRODUCTION

Awareness about quality of care is increasing among patients and the healthcare professionals.^{1,2} There is an increased incidence of inflammatory bowel disease (IBD), including chronic

inflammatory gastrointestinal-impaired ulcerative colitis (UC) and Crohn's disease (CD).³ IBD is a recurring disease requiring repeated hospitalization and long-term care,⁴ resulting in increased costs and frequent healthcare system utilization.⁵ As a result, IBD patients need appropriate and standardized care

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from diagnosis to drug therapy, acute and outpatient care, and are impacted by psychological and social aspects that are directly related to the quality of life.⁶ Several studies have focussed on the quality of care in IBD patients.⁷⁻¹⁰ To improve the quality of care of these patients, Donabedian's framework, which is composed of structure, process, and outcomes, can be used to set specific and measurable goals.^{1,11} Based on this framework, various quality indicators for IBD patients have been reported. Among them, the International Consortium for Health Outcomes Measurement is focused on the overall treatment outcome from diagnosis to palliative care or death.⁷ However, these quality indicators focus on assessing the appropriateness of IBD patient care for healthcare providers.

In recent years, patient awareness has also increased. Many studies have emphasized on patient reported out-

comes,^{12,13} and the trend is gradually shifting to personalized treatments based on the "treat to target" paradigm".^{14,15} In addition to treatment goals, different approaches, and treatment modalities are needed for each individual because each patient experiences treatment differently based on the disease course and their personal background.^{16,17} Therefore, understanding the patient's disease course and subjective thoughts are the key to improving the quality of care. For this study, we adopted the Q methodology, which can systematically analyze subjectivity.¹⁸ Subjectivity can be defined as one's thoughts, beliefs, values, and opinions about a particular phenomenon of interest of one or several people.¹⁹ The Q methodology is used to analyze such subjectivity by analyzing subjective opinion through objectification using the Q population theory and factor analysis.²⁰ To our knowledge, no

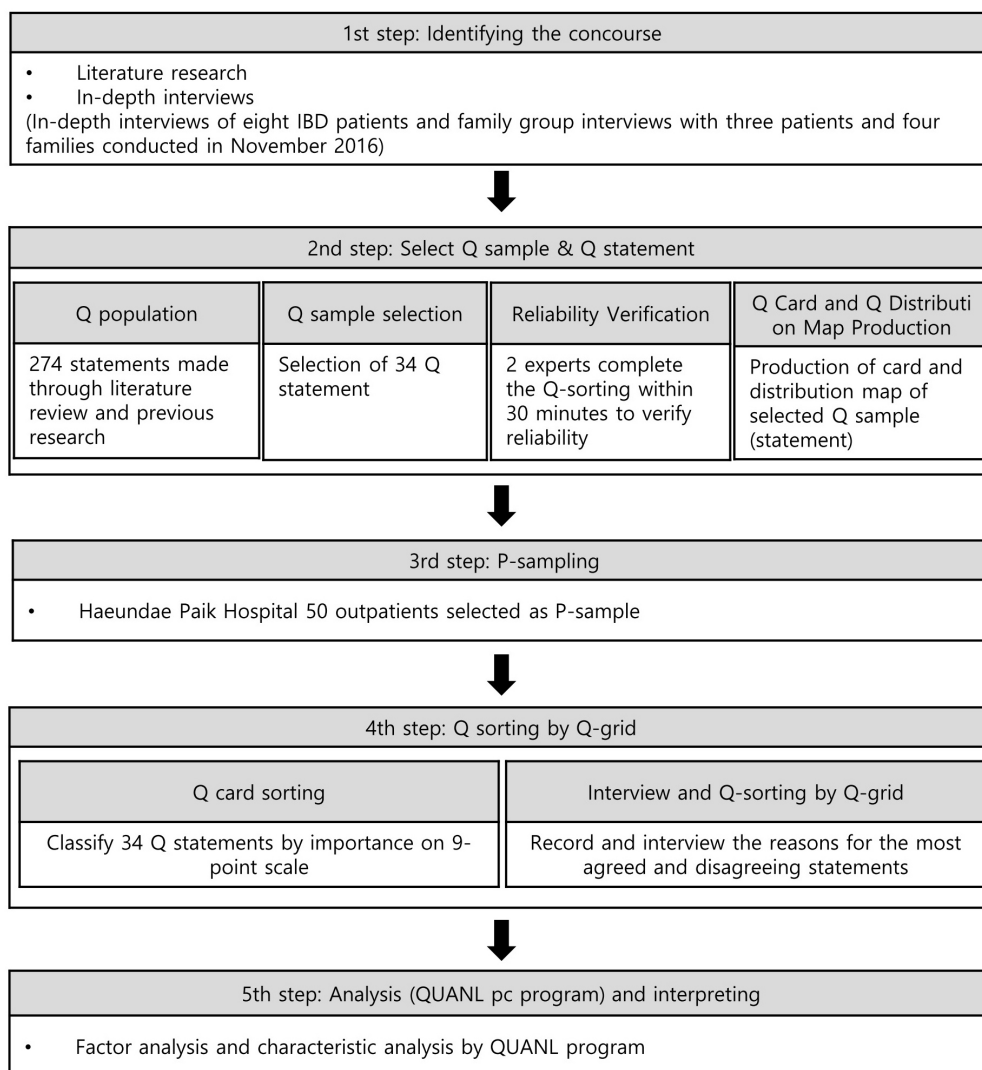


Fig. 1. Q methodology.

study to date has systematically analyzed the subjective thoughts and perspectives of IBD patients using the Q methodology. Therefore, this study aimed to identify the structural types and characteristics of the subjective and cognitive needs of treatment using the Q methodology in IBD patients.

SUBJECTS AND METHODS

1. Design: Q methodology

The Q methodology combines quantitative and qualitative techniques to study subjective phenomena systematically.^{18,21} The overall Q methodology implementation process is shown in Fig. 1.

2. Concourse development

The concourse is defined as “the flow of communicability surrounding any topic” in “the ordinary conversation, commentary, and discourse of everyday life”.²² The Q population is a collection of items collected for Q research, the same as the concept of a total concourse of opinions shared within a culture. The Q population is mainly used for literature research or in-depth interviews.²³ The subjects chosen for in-depth interviews for the Q population are expected to have both the same and different views.²⁴ As the concourse must capture the range of participant experiences (ex. first experience of diagnosis), a variety of sources are used to develop the concourse statements.

We enrolled IBD patients, including those with UC and CD diagnosed with clinical, endoscopic, histopathologic, and radiologic findings, in this study.^{21,25} In-depth interviews and focus family interviews were conducted by BAYADA Home Health Care Inc. to select a group in November 2016 for the Q population. In-depth interviews were conducted of eight patients (four males, four females; seven with CD, one with UC), and focus family group interviews were conducted of three patients and four of their family members for recognition categorization (Fig. 1).

3. Q sample and Q statement

Based on previous interviews and literature research, the Q population consisted of 274 statements. To select the Q samples, the 274 statements were repeatedly read to identify their common values and meanings and classified into the following 10 categories. Related items were as follows: diagnostic process, medical care team, diagnosis-treatment process (discomfort points), contact points, affected events, disease management efforts, social efforts, the role of medical personnel, questions, negative experiences and perceptions. Thirty-four finalized Q samples were selected for category statements of the same (positive), intermediate (neutral), or different (negative) meanings. Reliability was verified using a pretest on two selected researchers. On the pretest, both subjects were able to complete the Q sorting work within 30 minutes, and neither answered that the contents were

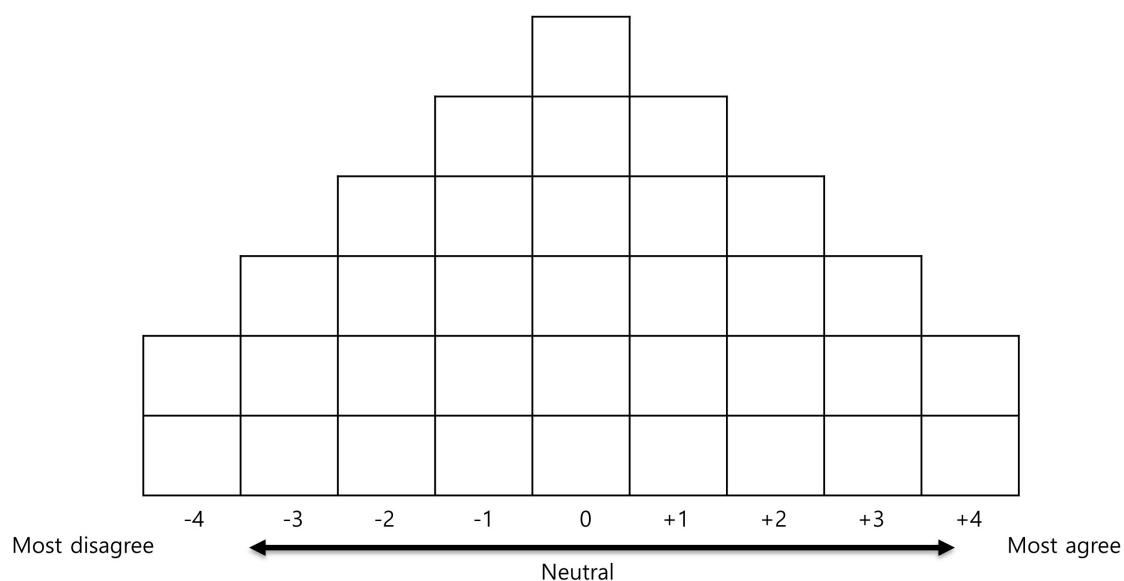


Fig. 2. Q- grid.

difficult. Q cards and distribution maps were subsequently produced (Fig. 1).

4. P sample

The P sample refers to respondents or subjects who actually participate in the Q sorting (i.e., Q sorter).²⁰ In the Q

Table 1. Demographics Characteristics (n=50)

Variables	Total (n=50)	CD (n=32, 64.0%)	UC (n=18, 36.0%)	p-value
Sex (male)	37 (74.0)	24 (64.9)	13 (35.1)	0.830
Age	27 (22-34)	31 (21-39)	26 (22-32)	0.191
Academic achievement				0.692
Middle school graduation	3 (6.0)	1 (3.1)	2 (11.1)	
High school graduation	17 (34.0)	11 (34.4)	6 (33.3)	
College graduate	4 (8.0)	3 (9.4)	1 (5.6)	
University graduation	26 (52.0)	17 (53.1)	9 (50.0)	
Religion				0.165
Atheism	39 (78.0)	28 (87.5)	11 (61.1)	
Buddhism	5 (10.0)	2 (6.3)	3 (16.7)	
Christian	4 (8.0)	1 (3.1)	3 (16.7)	
Catholic	2 (4.0)	1 (3.1)	1 (5.6)	
Marital status				0.021
Single	35 (70.0)	26 (81.3)	9 (50.0)	
Married	15 (30.0)	6 (18.8)	9 (50.0)	
Occupation ^a				0.660
Student	19 (38.0)	13 (40.6)	6 (33.3)	
Inoccupation	7 (14.0)	5 (15.6)	2 (11.1)	
Professions ^b	6 (12.0)	3 (9.4)	3 (16.7)	
Office workers ^c	12 (24.0)	8 (25.0)	4 (22.2)	
Skilled workers and related functional workers ^d	3 (6.0)	2 (6.3)	1 (5.6)	
Sales employees	1 (2.0)	0 (0)	1 (5.6)	
Public officer	1 (2.0)	0 (0)	1 (5.6)	
Temporary worker	1 (2.0)	1 (3.1)	0 (0)	
Time to diagnosis				0.524
<1 year	30 (60.0)	18 (56.3)	12 (66.7)	
1-3 years	13 (26.0)	10 (31.3)	3 (16.7)	
≥3 years	7 (14.0)	4 (12.5)	3 (16.7)	
Number of hospital to diagnosis				0.142
1	6 (12.0)	5 (15.6)	1 (5.6)	
2	28 (56.0)	14 (43.8)	14 (77.8)	
3	10 (20.0)	8 (25.0)	2 (11.1)	
≥4	6 (12.0)	5 (15.6)	1 (5.6)	
Duration of treatment				0.341
<1 year	5 (10.0)	3 (9.4)	2 (11.1)	
1-3 years	6 (12.0)	2 (6.3)	4 (22.2)	
3-5 years	17 (34.0)	10 (31.3)	7 (38.9)	
5-10 years	15 (30.0)	12 (37.5)	3 (16.7)	
≥10 years	7 (14.0)	5 (15.6)	2 (11.1)	
General condition				0.147
Well-being	9 (18.0)	8 (25.0)	1 (5.6)	
Good	23 (46.0)	15 (46.9)	8 (44.4)	
Usually	14 (28.0)	8 (25.0)	6 (33.3)	
Bad	4 (8.0)	1 (3.1)	3 (16.7)	
Very-bad	0 (0)	0 (0)	0 (0)	

Data are expressed as median (interquartile range, IQR) or number (%). p-value for comparing patients with CD and UC patients.

IBD, Inflammatory bowel disease; UC, Ulcerative colitis; CD, Crohn's disease.

^aOccupation groups are classified according to "Korean standard classification of occupations 7th edition"; ^bProfessions; pharmacist, researcher, shipyard, teacher, architect; ^cOffice workers; bank clerk, office worker, office worker, service industry; ^dSkilled workers and related functional workers; electric power production, manufacturing industry.

methodology, people are variables and items refer to samples, so the number of subjects is sufficient to generate factors and compare them between factors.²⁰ On the basis of this theory, this study constructed a P sample of 53 patients who visited the outpatient department of Haeundae Paik Hospital, Busan, Korea and agreed to participate in the study. This study was performed in accordance with the ethical guidelines of the 1975 Declaration of Helsinki and approved by the Institutional Review Board of Haeundae Paik Hospital, Busan, Korea (IRB No. HPIRB 2018-08-026-001).

5. Q sorting procedure

We conducted a brief survey and Q sorting of 53 outpatients from February to March 2019 at Haeundae Paik Hospital, Inje University College of Medicine, Busan, Korea. Three patients did not understand the Q sorting and were excluded due to insufficient analysis, resulting in a total of 50 patients. Q sorting refers to the process by which a respondent sorts Q samples and assigns a score to each.²⁰ The Q sorting process according to the forced normal distribution method is prepared by a Q sample distribution with a 9-point scale (Fig. 2; Q-grid). The two most negative (disagree) cards are placed at (-4), and the rest of the cards are arranged in the order of importance (-3)→(-1). The two most positive (agree) cards are placed in position at (+4), and the remaining cards are ranked and arranged according to importance (+3)→(+1). The neutral cards are placed in the (0) position, and the remaining cards are arranged in the remaining (+) or (-) space according to their importance. Finally, a simple survey was conducted with the reasons for the card selection.

6. Baseline patient characteristics

The baseline characteristics of the patients were obtained from a short survey and included patient demographics, academic achievements, religion, marital status, occupation, time to diagnosis, number of hospitals to diagnosis, treatment duration, and general conditions.

7. Data analysis

In the analysis of the data obtained through the Q sample classification process, the most negative questions were scored as -4 (1 point), -3 (2 points), -2 (3 points), -1 (4 points), 0 (5 points), +1 (6 points), +2 (7 points), +3 (8 points), and +4 (9 points) to be coded (Fig. 2). The 50 Q sorted data were analyzed using the QUANL PC program (version 1.2), while the Q factor analysis was performed using principal component factor analysis (varimax), and the results were used as important data for identifying the characteristics of each target type.

Variables are expressed as median (interquartile range [IQR]) or n (%). The baseline characteristics were compared using independent Student's *t*-test (or the Mann-Whitney test) for continuous variables and the χ^2 test (or Fisher's exact test) for categorical variables as appropriate. The baseline data were analyzed using SPSS software (version 25.0; IBM Corp., Armonk, NY, USA). *P* values <0.05 were considered statistically significant.

RESULTS

1. Baseline characteristics of the study participants

The baseline characteristics of the 50 IBD patients who

Table 2. Eigen Values, Variance, and Cumulative Percentage (n=50)

	Type 1	Type 2	Type 3	Type 4
Eigen value	13.9838	4.7493	2.4780	2.0484
Variance (%)	0.2797	0.0950	0.0496	0.0410
Cumulative variance	0.2797	0.3747	0.4242	0.4652

Table 3. Correlation Among Types

	Type 1	Type 2	Type 3	Type 4
Type 1	1.000			
Type 2	0.318	1.000		
Type 3	0.437	0.536	1.000	
Type 4	0.639	0.565	0.573	1.000

participated in the short survey and Q sorting are summarized in Table 1. A total of 50 patients with CD (n=32) and UC (n=18) visited the outpatient IBD clinic from February to March 2019 and participated in the study. The median patient age was 27 years (IQR 22-34 years); 37.0% of them were male, 70% were unmarried. The proportion of unmarried patients among those with CD was significantly higher (81.3% vs. 50.0%; $p=0.021$). There were no significant differences between the CD and UC groups in the other baseline

characteristics.

More than half of the subjects were highly educated (university graduation 52.0%), while 38% were students. Most participants did not declare a religion (78.0%). Most had been diagnosed with IBD less than 1 year prior (60.0%). In addition, 56% of the patients had visited a mean of two different clinics/hospitals before coming to our hospital; the treatment duration was generally 3-5 years (34.0%). This finding indicates that the treatment period is long but that the diagnosis is

Table 4. Q-statements and Z-scores According to Types

Q-statement	Z-score			
	Type 1	Type 2	Type 3	Type 4
I would like to help people who have similar symptoms in the future be diagnosed quickly.	1.52	0.71	1.70	0.92
It was too difficult to find a specialist for IBD in nearby hospital and local clinics.	0.01	-1.09	1.24	1.89
I found an IBD hospital on the Internet.	-0.59	-1.66	-0.67	-1.56
The medical staff is a very valuable person in overcoming my situation and is more important than a family living together.	1.31	0.32	-1.10	0.52
Just do what the hospital tells you to.	0.94	-1.56	-0.63	-0.63
Nurses are for hospitals, not for patients.	-1.37	-1.57	0.09	-1.65
When I get a referral from another department, it's hard to explain my condition as if I came to the hospital again.	-0.97	0.40	0.46	-0.37
The professionalism of the medical staff is the expertise of the disease and the experience of the patient.	1.63	1.71	2.04	1.95
Staff should basically have an attitude of understanding and responding to the patient.	1.39	1.60	1.04	1.20
I would like to listen to the stories of people who have overcome the problems of having a job.	0.06	0.36	0.04	0.26
What is diagnosed and immediately educated is neither memorable nor helpful.	-1.03	-0.50	-1.52	-1.84
If I ask any questions to the nurse, he or she says I should talk to a doctor.	-1.09	-0.68	-0.49	-1.31
If I have any questions, I can browse the Internet like a habit, but it's hard to find information that's right for me.	0.08	-0.21	-0.42	0.22
I think I should take care of myself because my doctor always tells me in a positive way.	1.26	-0.49	0.07	0.44
A family without a sick person does not know the pain.	-0.34	1.56	-0.24	0.70
I went to the hospital seminar only once or twice, but it does not help much.	-1.45	-0.76	-0.51	-1.26
Knowledge of the disease does not help.	-1.71	-1.12	-1.39	-1.18
I would like to have a medical staff who can answer my questions when I need them.	0.98	-0.24	1.07	0.95
I want disease education and counseling when I want to receive it.	-0.02	0.05	-0.87	-0.02
The stories of people with similar experiences are comforting.	0.68	-0.02	-1.16	0.03
It is helpful to say that rare and incurable diseases are used to distinguish diseases, and that there is no problem if you are managed well.	1.32	-1.08	-0.83	-0.22
I should understand the progress of my disease and find ways to manage it.	0.84	1.20	1.53	0.73
I don't want to make my family uncomfortable because of me.	-0.14	1.65	1.82	0.93
If I see a patient worse than me, I am determined not to be like that.	-0.26	0.15	1.34	-0.99
In order to maintain an ordinary life, we need to constantly fight ourselves.	0.92	0.63	1.34	0.26
It's hard to handle just having an unpredictable and difficult-to-treat disease.	-1.08	1.25	0.31	-0.50
When I go to a hospital seminar, it doesn't help because it seems like only the same attendees talk.	-1.62	-0.95	-1.33	-1.46
At first, I can't hear anything no matter what anyone says, but there are times when I get curious and information comes to my ears.	0.07	-0.85	-0.79	-0.69
There is hope when I hear about new treatments.	0.77	-0.31	0.23	0.82
Social awareness of rare diseases should change.	0.14	0.48	-0.66	1.22
We should continue to campaign for the understanding of IBD and social considerations.	-0.25	-0.02	-0.50	0.70
I feel energized when I have a medical staff who looks me in the eye and asks me questions.	0.22	0.03	-0.29	-0.62
It is not easy to meet medical staff working for patients.	-1.62	-0.86	-0.73	0.36
I want to know how to manage patients who have had long remission.	-0.62	1.85	-0.19	0.19

made relatively late. Most patients reported that their overall condition was relatively good (Table 1).

2. Formation and correlation of Q type

We evaluated the Q types of IBD patients for subjective phenomena. Four types accounted for 46.5% of the total variance: types 1, 2, 3, and 4 showed 28%, 9.5%, 5%, and 4.1%, respectively. The first type explained the attitude of IBD patients about their care (Table 2). The correlations among the four types of IBD patients are summarized in Table 3. A moderate correlation was seen in the degree of similarity among types ($r=0.32-0.64$), indicating that the types are relatively independent (Table 3).

3. Characteristics of the four subjective treatment need types

According to 34 Q statements (Table 4), four types of subjectivity regarding the treatment in IBD patients were classified. Tables 4, 5 show the results of each type of analysis of the standard score (Z-score) of the representative statements. Higher factor weights indicate more typical characteristics of the type.

1) Type 1: medial staff dependence type

A total of 20 patients (40%) were classified as type 1.

Patients of this type tended to show strong beliefs and dependence on the medical staff. There were 15 men (75.0%); the mean age was 25 years (IQR 20-38 years). The percentage of highly educated individuals was lower than that of the other types (45.0% vs. 60.0% vs. 54.5% vs. 55.6%; $p=0.611$). Compared to other types, the proportion of patients diagnosed within 1 year was higher (65% vs. 60% vs. 54.5% vs. 55.6%; $p=0.385$) (Supplementary Table 1).

Q statements with a Z-score greater than 1.0 included: "The professionalism of the medical staff is the expertise of the disease and the experience of the patient"; "I would like to help people who have similar symptoms in the future be diagnosed quickly"; "Staff should basically have an attitude of understanding and respond to the patient"; "It is helpful to say that rare and incurable diseases are used to distinguish diseases and that there is no problem if you are managed well"; "The medical staff is very valuable to my overcoming my situation and is more important than a family living together"; and "I think I should take care of myself because my doctor always talks to me in a positive way".

However, they most often disagreed with the following statements: "What is diagnosed and immediately educated is neither memorable nor helpful"; "Nurses are for hospitals, not for patients"; "I went to the hospital seminar only once or twice, but it does not help much"; "When I go to a hospital

Table 5. Q-statements and Z-scores according to types

Points	Type 1 (medical staff-dependent type)	Type 2 (relationship-oriented type)	Type 3 (information-oriented type)	Type 4 (social awareness type)
Z-score ≥1.0	8. Medical professionals 1. I want to help 9. Urging attitude of medical staff 21. Helpful words 4. The Importance of Medical Staff 14. Positive medical staff's attitude	34. Relationship maintenance method 8. Medical professionals 23. Family discomfort 9. Urging attitude of medical staff 15. The pain of the family 26. Unbearable disease 22. Find disease management methods	8. Medical professionals 23. Family discomfort 1. I want to help 22. Find disease management methods 25. A constant fight 24. Other patient's consolation 2. Difficulty in finding a professional faculty 18. Helpful Medical staff 9. Urging attitude of medical staff	8. Medical professionals 2. Difficulty in finding a professional faculty 30. Change in social awareness 9. Urging attitude of medical staff
Z-score <-1.0	11. No immediate education required 26. Unbearable disease 12. Attitude of the nurse 6. Nurses for hospitals 16. Unhelpful hospital seminar 27. Same attendee 33. Medical staff for me 17. Knowledge of illness that is not helpful	21. Helpful words 2. Difficulty in finding a professional faculty 17. Knowledge of illness that is not helpful 5. Implementing Hospital Directives 6. Nurses for hospitals 3. Internet search	4. The Importance of Medical Staff 20. Other patient's experience 27. Same attendee 17. Knowledge of illness that is not helpful 11. No immediate education required	17. Knowledge of illness that is not helpful 16. Unhelpful hospital seminar 12. Attitude of the nurse 27. Same attendee 3. Internet search 6. Nurses for hospitals 11. No immediate education required

seminar, it does not help because it seems like only the same attendees talk”; and “It is not easy to meet medical staff working for patients” (Table 5).

Common consent items for this type of patient are important for trust in the medical team and the belief that the condition will improve if the hospital provides the treatment. They are encouraged by positive comments from the medical staff and strongly want to help treat patients with similar symptoms who have not been properly diagnosed but have received wrong folk remedies. Hospital seminars are also helpful because patients can meet people with similar symptoms while hearing various lectures.

2) Type 2: relationship-oriented type

A total of 10 patients (20%) were classified as type 2. They value the professionalism of the medical staff, but they think they should be aware of the disease and know how to manage it themselves. They are also strongly burdened by the disease itself, the related pain, and the concerns of their family and neighbors. Patients of this type were 90% male and younger than those of other types (mean age, 24 years). Sixty percent of the patients of this type were the most highly educated, with college degrees ($p=0.611$), and most were single (90.0%). Seventy percent of these patients had CD, and more patients from this group were diagnosed more than three years prior than the other types (type 1, 2, 3, and 4; 15.0% vs. 30.0% vs. 9.1% vs. 0%; $p=0.385$). In addition, many patients tended to think that their overall condition was poor (type 1, 2, 3, and 4; 5.0% vs. 20% vs. 9.1% vs. 0%; $p=0.496$) (Supplementary Table 1). This finding indicates that they are more likely to believe that they should manage the disease on their own, expecting to consult the medical staff as they experience various courses of the disease during the treatment period.

The Q statements with a Z-score >1.0 include the following: “I want to know how to manage patients who have had long remission periods”; “The professionalism of the medical staff is the expertise of the disease and the experience of the patient”; “I do not want to make my family feel uncomfortable because of me”; “Staff members should be understanding and responsive to patients”; “People without a sick person in their family do not understand the pain”; and “It is difficult to handle an unpredictable and difficult-to-treat disease”.

The patients most often disagreed with the following

statements: “It is helpful to say that rare and incurable diseases are used to distinguish diseases and that there is no problem if you manage it well”; “It was too difficult to find a specialist for IBD at nearby hospitals and local clinics”; “Just do what the doctors tell you to do”; “Nurses are for hospitals, not for patients”; and “I found an IBD hospital on the internet” (Table 5).

The patients with the highest factor weights were type 2 and said that those who did not experience the disease could not understand the pain and the family’s concerns; one stated that he did not want his family to feel uncomfortable because of him. He also said that people are not familiar with CD, which makes it difficult for him to obtain the time and financial means required to obtain proper treatment.

3) Type 3: information-driven type

A total of 11 patients (22%) were classified as type 3. Rather than being affected by the experiences or circumstances of other patients, they want to be provided with information and healthcare that is helpful to them. Compared to other types, they strongly value the need for clinicians to answer questions when they need them. However, they have a strong desire to know about their disease and how to manage a worsening situation. This group was composed of a higher proportion of married people than the other types (type 1, 2, 3, and 4; 35% vs. 10% vs. 45.5% vs. 22.2%; $p=0.301$). CD, which can show various disease courses and complications, was seen in 80% of affected patients, who made many hospital visits before being diagnosed (Supplementary Table 1).

The Q statements with a Z-score >1.0 included: “The professionalism of the medical staff is the expertise of the disease and the experience of the patient”; “I would like to help people who have similar symptoms in the future be diagnosed quickly”; “I should understand my disease and find ways to manage it”; “To maintain an ordinary life, we must constantly fight ourselves”; “It was too difficult to find a specialist for IBD at a nearby hospital or clinic”; “I would like to have access to a medical staff member who can answer my questions when I have them”; and “Staff members should be understanding and responsive to patients”.

The patients most often disagreed with the following statements; “The medical staff is a very valuable person in overcoming my situation and more important than a family member”; “Stories of people with similar experiences are comfort-

ing”; “When I go to a hospital seminar, it does not help because it seems like the same attendees talk”; “Knowledge of the disease does not help”; and “What is diagnosed and immediately educated is neither memorable nor helpful” (Table 5).

The commonly mentioned statements of this type of patient were the importance of medical professionalism and disease knowledge as well as the importance of knowing themselves. Most patients of this type revealed through the survey that they wanted to find good information, understand their disease, and find ways to manage it.

4) Type 4: social awareness type

A total of nine patients (18%) were classified as type 4, a type that calls for changes in reality and social awareness that require not only basic medical expertise but also efficient access to specialized hospitals and medical staff. These patients value knowledge, education, and seminars and think that nurses should be the people who actively care for affected patients. Of the four types, the average age was the highest (type 1, 2, 3, and 4; 25 years vs. 24 years vs. 28 years vs. 31 years; $p=0.559$), and participants had the highest employment rate. In addition, patients who had been treated for more than 10 years accounted for 33% of this type (type 1, 2, 3, and 4; 0% vs. 20% vs. 18.2% vs. 33.3%; $p=0.584$) (Supplementary Table 1).

The Q statements with a Z-score >1.0 included: “The professionalism of the medical staff is the expertise of the disease and the experience of the patient”; “It was too difficult to find a specialist for IBD at a nearby hospital or clinic”; “Social awareness of rare diseases should change”; and “Staff members should be understanding and responsive to patients”.

However, they most often disagreed with the following statements: “Knowledge of the disease does not help”; “I went to the hospital seminar only once or twice, but it does not help much”; “If I ask the nurse any questions, he or she says I should talk to a doctor”; “I found an IBD hospital on the internet”; and “Nurses work for hospitals, not for patients” (Table 5).

Some patients had a hard time understanding their exact diagnosis and mentioned that local hospitals and clinics are not well aware of the disease and that it is difficult to find professional medical staff. Another patient emphasized the

need for people’s consideration of and attention to IBD patients due to changes in social awareness. Some also said that they received better information through seminars with medical staff since there was a lot of wrong information on the internet.

4. Consensus between views

The four commonly agreed statements of subjectivity regarding the disease-related attitudes in IBD patients are: “The professionalism of the medical staff is the expertise of the disease and the experience of the patient”; and “Staff members should be understanding and responsive to patients”. However, all types of patients disagreed with the following statement: “Knowledge of the disease does not help”.

DISCUSSION

Despite advances in the treatment of IBD²⁶ and improvements in healthcare quality, IBD patients still struggle with treatment, complicated management, and quality of life. Therefore, it is important that we not only improve the quality of care but also understand patient perceptions of the disease and treatment process to provide personalized care. Our study is an objective analysis using the Q methodology to determine what patients think of the disease and what words and processes were helpful and difficult while receiving treatment. Our findings showed four types of IBD patients, including medical staff-dependent, relationship-oriented, information-driven, and social awareness, with slightly different values regarding what patients need.

With the increasing awareness and interest in IBD due to chronic care diseases with a large number of young patients, efforts to measure the quality of care from the patients’ perspective are also increasing.^{2,12,27} Soares et al.¹² reported the validation of the Portuguese version of a questionnaire to measure the quality of care through the eyes of patients with inflammatory bowel disease (QUOTE-IBD). They analyzed 9 dimensions of the QUOTE-IBD: total care, accessibility, accommodation, autonomy, competence, continuity of care, cost, courtesy, and information. Most items had reliable results; however, they reported no significant difference in disease type or quality of life associated with activity or health. Therefore, more research is needed because of the lack of tools available to evaluate the quality of care from the patient

perspective. Thus, it was meaningful to analyze subjectivity from the patient's perspective in this study.

In our study, many type 1 patients (medical staff-dependent) thought that they should trust the medical staff and follow their instructions. Considering the fact that many patients were diagnosed less than one year prior to this study, it can be expected that their thoughts and perspectives may vary depending on the length of time since diagnosis. In type 2 patients (relationship-oriented), the burden on family interests and suffering was greater than that of other types. One patient said that even though the pain was not caused by IBD, it was considered a symptom of IBD and was not treated well. It is difficult to explain the disease; therefore even family members do not understand the patient's condition well. Through this study, we found that the families of patients also require education and mental support, and communication. Type 3 patients (information-driven) expressed similar thoughts as those of types I and II. Medical expertise, willingness to help, and unwillingness to be a burden on the family were similar, but compared to other types, they tended to have a strong desire to solve, manage, and understand the disease on their own. This type of patient wanted to know how to manage the disease so that it would not worsen and how they could control it, especially with food choices. Thus, detailed explanations and options even during the drug decision process can be helpful for these patients, and counseling with nutritionists and multidisciplinary teams can be of great help. Type 4 patients (social awareness) tend to pay attention to social awareness, as this type includes several long-term patients who have been treated for more than 10 years. In fact, IBD remains recognized as a rare disease in Korea, and it is often seen as embarrassing for workers if colleagues around them come to know about the condition. Therefore, most patients do not talk about the disease because it is difficult to explain. To change the perception of IBD, it is necessary to publicize disease information and show that good management can lead to a life without difficulties. However, social efforts are still lacking. Therefore, it is necessary to first explore ways to help patients with IBD from the hospital side, such as making accessible toilets and forming multi-disciplinary teams.

Our study, the first using Q methodology in IBD patients, shows strong advantages in terms of analyzing the subjectivity of patients divided into four types. However, our study had

several limitations. Firstly, only a relatively small number of outpatients were enrolled, which can lead to selection bias. For example, since the questions that make the statement of the Q-methodology are chosen by particular researchers, a researcher-related selection bias may occur, especially with a small number of subjects. However, such risks are minimized since the researchers who choose the statements are experts who have implemented the Q-methodology several times. In addition, although it is meaningful to investigate outpatients in consistent and stable circumstances because we wanted to observe the quality of care, further studies would be beneficial with more patients, including inpatients. Secondly, we could not conduct in-depth interviews of all patients and their related family members. Although in-depth interviews were conducted for Q sampling, the number of participants was small. Finally, there is a limitation in that we did not investigate the clinical information such as disease activity, clinical course, medications, and adherence of patients together. Therefore, further well-designed studies with large populations are needed in the future. However, the types of IBD patients classified in our study will be an important data input in developing patient-customized quality of care models.

In summary, here we used Q methodology to divide the subjective thoughts of IBD patients into four types: medical staff-dependent, relationship-oriented, information-driven, and social awareness. In this study, we realized that patients wanted the expertise of the medical staff, wanted to learn about the disease and were helped by seminars. These results will provide basic information to help patients understand and provide care from the IBD patients' perspective.

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Supplementary Table 1. Demographics Characteristics Among Q-types (n=50)

Variables	Type 1 (n=20)	Type 2 (n=10)	Type 3 (n=11)	Type 4 (n=9)	p-value
Sex (male)	15 (75.0)	9 (90.0)	8 (72.7)	5 (55.6)	0.401
Age	25 (20-38)	24 (21-33)	28 (23-36)	31 (25-34)	0.559
Academic achievement					0.611
Middle school graduation	2 (10.0)	1 (10.0)	0 (0.0)	0 (0.0)	
High school graduation	7 (35.0)	3 (30.0)	5 (45.5)	2 (22.2)	
College graduate	2 (10.0)	0 (0.0)	0 (0.0)	2 (22.2)	
University graduation	9 (45.0)	6 (60.0)	6 (54.5)	5 (55.6)	
Religion					0.145
Atheism	16 (80.0)	7 (70.0)	10 (90.9)	6 (66.7)	
Buddhism	3 (15.0)	1 (10.0)	0 (0.0)	1 (11.1)	
Christian	1 (5.0)	0 (0.0)	1 (9.1)	2 (22.2)	
Catholic	0 (0.0)	2 (20.0)	0 (0.0)	0 (0.0)	
Marital status					0.301
Single	13 (65.0)	9 (90.0)	6 (54.5)	7 (77.8)	
Married	7 (35.0)	1 (10.0)	5 (45.5)	2 (22.2)	
Occupation ^a					0.594
Student	5 (25.0)	5 (50.0)	6 (54.5)	3 (33.3)	
Inoccupation	5 (25.0)	0 (0.0)	1 (9.1)	1 (11.1)	
Professions ^b	3 (15.0)	1 (10.0)	1 (9.1)	1 (11.1)	
Office workers ^c	6 (30.0)	3 (30.0)	1 (9.1)	2 (22.2)	
Skilled workers and related functional workers ^d	0 (0.0)	1 (10.0)	1 (9.1)	1 (11.1)	
Sales employees	0 (0.0)	0 (0.0)	1 (9.1)	0 (0.0)	
Public officer	1 (5.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Temporary worker	0 (0.0)	0 (0.0)	0 (0.0)	1 (11.1)	
Diagnosis					0.334
UC	10 (50.0)	3 (30.0)	2 (18.2)	3 (33.3)	
CD	10 (50.0)	7 (70.0)	9 (81.8)	6 (66.7)	
Time to diagnosis					0.385
<1 year	13 (65.0)	6 (60.0)	6 (54.5)	5 (55.6)	
1-3 years	4 (20.0)	1 (10.0)	4 (36.4)	4 (44.4)	
≥3 years	3 (15.0)	3 (30.0)	1 (9.1)	0 (0.0)	
Number of hospital to diagnosis					0.077
1	1 (5.0)	1 (10.0)	4 (36.4)	0 (0.0)	
2	11 (55.0)	7 (70.0)	3 (27.3)	7 (77.8)	
3	6 (30.0)	2 (20.0)	1 (9.1)	1 (11.1)	
≥4	2 (10.0)	0 (0.0)	3 (27.3)	1 (11.1)	
Duration of treatment					0.584
<1 year	4 (20.0)	0 (0.0)	1 (9.1)	0 (0.0)	
1-3 years	3 (15.0)	1 (10.0)	1 (9.1)	1 (11.1)	
3-5 years	6 (30.0)	4 (40.0)	4 (36.4)	3 (33.3)	
5-10 years	7 (35.0)	3 (30.0)	3 (27.3)	2 (22.2)	
≥10 years	0 (0.0)	2 (20.0)	2 (18.2)	3 (33.3)	
General condition					0.496
Well-being	6 (30.0)	2 (20.0)	1 (9.1)	0 (0.0)	
Good	8 (40.0)	3 (30.0)	6 (54.5)	6 (66.7)	
Usually	5 (25.0)	3 (30.0)	3 (27.3)	3 (33.3)	
Bad	1 (5.0)	2 (20.0)	1 (9.1)	0 (0.0)	
Very-bad	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	

Data are expressed as median (interquartile range, IQR) or number (%). p-value comparing Q types.

UC, ulcerative colitis; CD, Crohn's disease.

^aOccupation groups are classified according to "Korean standard classification of occupations 7th edition"; ^bProfessions; pharmacist, researcher, shipyard, teacher, architect. ^cOffice workers; bank clerk, office worker, office worker, service industry. ^dSkilled workers and related functional workers; electric power production, manufacturing industry.