











Questionnaire Survey of Japanese Patients With Inflammatory Bowel Disease and Physicians on Shared Decision-Making in Advanced Therapy: A Web-Based PAIR Survey

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Abstract

Background/Aims: With the recent increase in available treatment options for inflammatory bowel disease (IBD), shared decision-making has gained considerable importance. To address potential disparities in patient and physician priorities, we conducted a survey to clarify these perspectives.

Methods: Patients with IBD and physicians treating IBD were asked to complete an online questionnaire focused on key factors influencing drug selection and preferred drug administration methods.

Results: Responses were obtained from 400 patients (327 with ulcerative colitis and 73 with Crohn's disease) and 155 physicians. Among the factors in drug selection, physicians assigned significantly higher importance scores for experience with the drug than did patients. The expected time to onset of drug effects was significantly different between patients and physicians. Regarding preferences for drug administration method, patients and physicians assigned the highest acceptability scores for once-daily oral administration. For intravenous and subcutaneous routes, patients' scores were significantly lower than those of physicians' scores. Notably, 86.0% of patients and 62.0% of physicians preferred oral administration as the most preferred method. However, preferences varied based on treatment experience: 34.7% of patients with prior experience with subcutaneous injection preferred this method.

Conclusions: Patients and physicians generally shared similar priorities for drug selection; however, physicians emphasized their experience with the drug over patient preferences. Although the number of patients with prior treatment experience preferred intravenous or subcutaneous injections, oral formulations remained the preferred choice for both patients and physicians.

Lay Summary

An internet-based survey of patients with inflammatory bowel disease and treating physicians was conducted in Japan. The survey clarified the similarities and differences patients and physicians prefer and what they consider important in treatment decisions, as well as administration methods.

Key Words: ulcerative colitis, Crohn's disease, inflammatory bowel disease, preference, shared decision-making

Introduction

Inflammatory bowel disease (IBD), which includes ulcerative colitis (UC) and Crohn's disease (CD), is a chronic condition of unknown etiology.¹ Patients with IBD experience diarrhea, abdominal pain, fever, weight loss, and bloody stools, which considerably impaired their quality of life.² Although the prevalence of IBD varies by region and country, IBD has been increasing in recent years, due in part

to environmental changes, dietary changes, and genetic predisposition.^{3,4} Current treatment options for refractory IBD include antitumor necrosis factor antibody, anti-p40 antibody, anti-p19 antibody, anti- $\alpha 4\beta 7$ integrin antibody, janus kinase inhibitors, and sphingosine 1-phosphate receptor modulators.⁵⁻¹⁵ These drugs can be administered through various routes, including oral, intravenous, or subcutaneous, in differing frequencies. Although guidelines have

been provided for the treatment of IBD, there are many therapeutic agents and not all of them are clear on how to choose.^{16–19}

Patients and physicians often differ in their treatment priorities, underscoring the need for shared decision-making (SDM).^{20,21} When selecting a drug, in addition to efficacy, safety, and drug information, patient acceptability should also be considered.^{22,23} However, patient and physician perceptions may not always align, which can impact treatment adherence and quality of the doctor-patient relationship. To better understand these perspectives, we conducted the PAIR survey (Patients with IBD and doctors), an internet-based survey to explore the priorities of both patients and physicians in drug selection and convenience of administration methods.

Methods

Survey Instruments

Surveys were conducted by the Cross Marketing Corporation (Tokyo, Japan) targeting both IBD patients and physicians treating IBD. The survey of IBD patients was conducted between August 2 and 8, 2024, inviting 492 IBD patients nationwide (403 with UC, 89 with CD) to participate in an online questionnaire survey. Among them, 400 patients (327 with UC, 73 with CD) agreed to participate in the survey and consented to the disclosure of results. The physician's survey was conducted online from August 8 to 9, 2024, inviting all specialties 33 257 physicians nationwide, and 155 physicians who treated at least 5 patients with IBD responded.

The survey questionnaire for patients included the following items: type of disease (UC/CD), disease duration of IBD, smoking status, occupation, history of bowel resection, history of hospitalization, type of attending institution, severity of symptoms (degree of diarrhea and abdominal pain on a 4-point scale of none/ mild/ moderate/ severe), current treatment methods, experience with drug selection, importance of efficacy, safety, convenience of administration, cost of the drug, experience with the drug, physician's recommendation in drug selection (importance scores rated on a scale of 1–5), expected time to onset of drug effects, preference of administration method (acceptability scores on a scale of 1–10), the most preferred method of administration, evaluation of the usefulness of oral administration (on a scale of 1–10), most perceived benefit of oral administration. The survey items for physicians included age, sex, type of medical institution and department, number of patients treated for UC and CD, criteria for selecting advanced therapies, importance of efficacy, safety, convenience of administration, cost of the drug, experience with the drug, and revenues of medical institutions in drug selection (importance scores on a scale of 1–5), expected time to onset of drug effects, preference for administration methods (acceptability scores on a scale of 1–10), the most preferred method of administration, and evaluation of the usefulness of oral administration (on a scale of 1–10), and the advantages of oral administration. Informed consent from both patients and physicians was obtained online for conducting and publishing the results of the survey.

Outcome

The primary endpoint was the comparison of acceptability scores from 1 (least preferred) to 10 (most preferred) for the 9 drug administration methods and the differences in these

scores between patients and physicians. Secondary endpoints included the most preferred drug administration method, importance scores for various drug selection factors from 1 (not important) to 5 (very important), evaluation of the usefulness of oral administration scores from 1 (not good) to 10 (very good), most useful merit of oral administration, expected time to onset of drug effect, and the difference between patients' and physicians' responses.

Statistical Analysis

All statistical analyses were performed using the SAS software (version 9.4; SAS Institute Japan Ltd.). Statistical analysis was conducted using the Pearson chi-square test for categorical data and the Mann–Whitney U test or Wilcoxon signed-rank test for continuous variables. A *P*-value < .05 was considered statistically significant.

Results

Demographics of the Patients and Physicians

Responses were received from 400 patients (327 with UC, 73 with CD) and 155 physicians, and all patients and physicians who responded were included in this questionnaire survey. All responses were eligible and included in the analysis. The mean age of IBD patients was 53.1 years, mean duration of disease was 16.0 years, and 66.5% of the patients were men (Table 1). Occupational status was full-time (50.8%), part-time (16.5%), student (0%), housework (8.8%), other (4.8%), and unemployed (19.3%). Diarrhea, abdominal pain, and other subjective symptoms were not present in 42.5% of the patients, mild in 40.3%, moderate in 15.5%, and severe in 1.8%. The mean age of the physicians was 49.3 years, 99.5% were men, and 61.3% were gastroenterologists (Table 2). The average number of patients treated per physician was 23.7 UC patients and 14.1 CD patients.

Experience and Method of Drug Selection

Among the patients, 34.5% reported that their physicians had presented them with multiple drug options, allowing them to make the final choice. Regarding the physicians' approach to drug selection, 18.2% indicated that they presented all the drug options and let the patient make the decision. In contrast, 54.1% indicated that the physician narrowed down the available drug options and let the patient make the decision, and 27.8% indicated that the physician chose the drug (Figure S1).

Importance in Drug Selection

In drug selection, the importance scores for safety and drug cost were not significantly different between patients and physicians. However, patients assigned significantly lower importance scores for efficacy and higher importance scores for convenience than did physicians, although the differences were not so large (*P* = .0013 and *P* = .0420, respectively). Compared with patients, physicians assigned significantly higher importance scores for experience with the drug (*P* < .0001) (Figure 1).

Expected Time to Onset of Drug Effect

Regarding expected time to onset of drug effect, a significant difference was observed between the 2 groups (*P* < .0001). Among the physicians, 42.6% expected the drug to be

Table 1. Demographic characteristics of the patients.

Number of patients	400
UC	81.8% (327/400)
CD	18.3% (73/400)
Sex (male)	66.5% (266/400)
Age (mean \pm SD)	53.1 \pm 11.2 years
Disease duration (mean \pm SD)	16.0 \pm 10.8 years
Working status	
Full-time	50.8% (203/400)
Part-time	16.5% (66/400)
Student	0% (0/400)
Housework	8.8% (35/400)
Other	4.8% (19/400)
Unemployed	19.3% (77/400)
Smoking	
Never	49.5% (198/400)
Present	16.8% (76/400)
Past	33.8% (135/400)
History of resection	16.5% (66/400)
Number of hospitalizations (mean \pm SD)	2.2 \pm 5.2
Severity of current symptoms	
None	42.5% (170/400)
Mild	40.3% (161/400)
Moderate	15.5% (62/400)
Severe	1.8% (7/400)
Visiting institutions	
University hospital	21.0% (84/400)
General hospital	52.8% (211/400)
Clinic	25.8% (103/400)
No regular visits	0.5% (2/400)
Treatment history	
Oral therapy	96.3% (385/400)
Nutritional therapy	19.3% (77/400)
Infusion or injection therapy	34.0% (136/400)
Self-injection therapy	12.3% (49/400)
Topical therapy	46.8% (187/400)
Other	2.3% (9/400)
None	1.3% (5/400)

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

effective within 1 month and 11.6% within 1 week, whereas 60.3% of patients expected the drug to be effective within 1 week (Figure 2).

Preference for Administration Methods

Among patients, once-daily oral administration had the highest acceptability score, with significant differences between oral administration twice daily and intravenous infusion at each dosing interval, and subcutaneous injection at each dosing interval ($P < .0001$) (Figure 3). Similarly, physicians also assigned the highest acceptability scores for once-daily oral administration, with significant differences between oral administration twice daily, intravenous infusion at each dosing interval, and subcutaneous injection at each dosing interval ($P < .0001$). For intravenous infusions or subcutaneous

Table 2. Physicians' demographic characteristics.

Number of physicians	155
Sex (male)	95.5% (148/155)
Age (mean \pm SD)	49.3 \pm 10.0 years
Medical institution	
University hospital	21.3% (33/155)
General hospital	61.9% (96/155)
Clinic	16.8% (26/155)
Specialization	
Gastroenterology	61.3% (95/155)
Surgery	11.6% (18/155)
General physician	25.2% (39/155)
Other	1.9% (3/155)
Number of patients treated	
IBD	37.8 \pm 57.7
UC	23.7 \pm 38.5
CD	14.1 \pm 21.1

CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

injections, patients with prior experience with these methods assigned higher scores than those with no prior experience; however, the once-daily oral formulation remained the most preferred method with highest acceptability scores (Figure S2). The acceptability scores for oral treatment were similar between patients and physicians, whereas patients' scores for intravenous and subcutaneous routes were significantly lower than those of physicians' scores. Regarding the most preferred method of administration, 72.5% of patients preferred once-daily oral administration, and 86.0% preferred oral administration when twice daily was included. Moreover, physicians preferred once-daily oral administration, with 58.7% indicating it as their top choice, and 62.0% preferred oral administration when twice-daily dosing was included; however, this was significantly lower than those indicated by patients ($P < .0001$) (Figure 4). Results by patients' treatment experience are shown in Figure S3.

Usefulness of Oral Administration

In the patients' evaluation of the usefulness of oral administration, high scores were given for several items. The most valued advantage was the "freedom to take the medication at any time and place" (32.0%), followed by "short time required for administration" (23.8%), and the "absence of injection-related fear or pain" (16.5%) (Figure 5). Similarly, oral administration was rated high by the physicians for several reasons, including ease and quick prescription (33.5%), less burden on medical staff for administering the medication (19.4%), and the avoidance of puncture or injection-induced pain for patients (17.4%) (Figure 6).

Discussion

Although mutual agreement between physicians and patients is crucial in treating IBD, a gap often exists between the perceptions of physicians and patients.²⁴⁻²⁶ With the development of new drugs that can be administered orally, intravenously, or subcutaneously at different frequencies,⁵⁻¹⁵

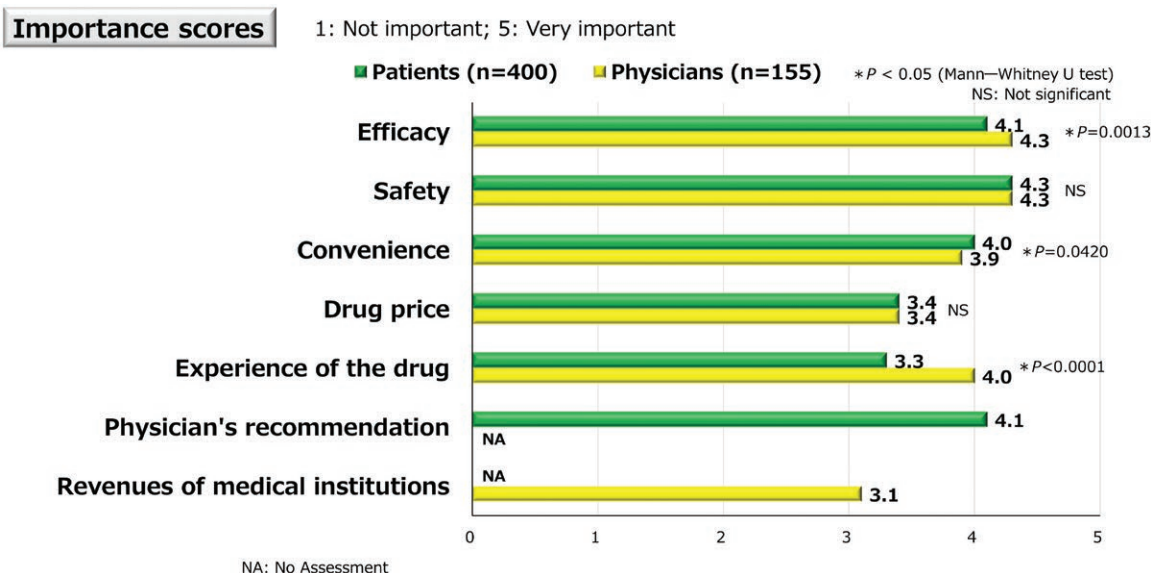


Figure 1. Importance in drug selection. The 5-level importance scores in drug selection between patients and physicians. Although the differences between patients' and physicians' scores were not large, patients assigned significantly lower importance scores for efficacy and higher importance scores for convenience than those of physicians ($P = .0013$ and $P = .0420$, respectively). Compared with patients, physicians had significantly higher importance scores for experience with the drug ($P < .0001$).

SDM has become increasingly important in the treatment of IBD.^{20,21} Effective drug selection requires consideration of efficacy, safety, and drug information, in addition to patient acceptability.^{22,23} This online-based survey aimed to investigate both patients' and physicians' priorities when selecting advanced therapies for IBD and their preferences for administration methods. The low physician response rate is due to the fact that the survey panel was registered from all specialties, and only physicians with experience with IBD responded to the survey.

Given the challenges in predicting the efficacy and adverse effects of IBD treatments, SDM is a beneficial approach for selecting a drug from among various advanced therapies. However, with the increasing number of available advanced therapies, time constraints make it difficult to present all options. Notably, our survey results indicated that only 18.2% of physicians indicated that they presented all available drug options, whereas 54.1% of physicians narrowed down the list. While the traditional paternalistic approach of the doctor-patient relationship is decreasing, SDM is being implemented in a more practical and time-efficient manner in real clinical practice. This study highlights that SDM, which is applied as an approach known as "libertarian paternalism," is being used in clinical practice. In the past, the choice of treatment was generally based on the so-called paternalism, in which the patient accepts the treatment proposed by the doctor. However, SDM is now recommended, and doctors are expected to support patients' decision-making as the expert while respecting their preferences and free will.²⁷ On the other hand, in cases where there are many treatment options, such as in the field of IBD, simply presenting a lot of options can often confuse patients and make it more difficult for them to choose.²⁸ To solve this problem of difficulty in choosing a treatment, the method of "libertarian paternalism" is thought to be effective. Libertarian paternalism is a concept that is a combination of paternalism and libertarianism.²⁹ For example, narrowing down the options and recommending them

from many treatment options is thought to be a concrete example of libertarian paternalism. In that case, it is important to consider the patient's lifestyle and preferences, rather than just the stereotypical patient's medical condition.

Regarding the importance of each item in patient and physician drug selection, patients and physicians had assigned similar importance scores for efficacy, safety, convenience, and drug cost; however, physicians assigned significantly higher importance scores for experience with the drug than did patients. This suggests that physicians may emphasize their experience with certain drugs. Regarding the expected time to onset of the drug effect, 60% of patients expected the drug to be effective within 1 week, whereas only 12% of physicians anticipated this outcome. The percentage of patients expected the drug to be effective within 1 week, which aligns with the results of a survey on patients with rheumatoid arthritis.^{30,31} Recently, there have been an increasing number of study reports about early efficacy, but realistically, efficacy rates in the 1 week or 2 weeks after administration are never as high as patients would like.^{32–36} The lower percentage of physicians expecting the drug to be effective within 1 week may reflect a perceived practical difficulty. Nonetheless, this represents a gap in expectations, as most patients expect quick relief. To better align with IBD patients' needs, physicians should consider earlier symptom improvement wherever feasible. The expected time to efficacy may differ depending on the severity of symptoms, but no notable differences were observed, due in part to the small number of patients with moderate or severe symptoms in this study.

Among the 9 administration methods evaluated, patients assigned the highest acceptability scores for once-daily oral administration, with 86.0% of patients preferring oral administration, which aligns with that of previous studies.^{37–40} Patients with prior experience with subcutaneous and intravenous formulations showed improved acceptance to these methods,^{38,41} and patients with prior treatment also assigned higher scores for these formulations; however, the

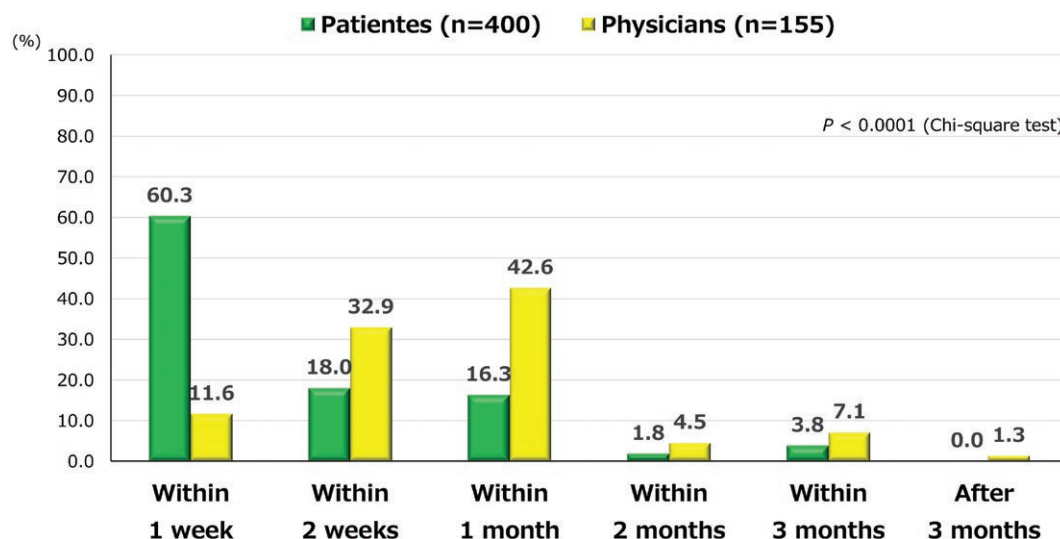


Figure 2. Expected time to onset of drug effect. The expected time to onset of drug effects was significantly different between patients and physicians ($P < .0001$).

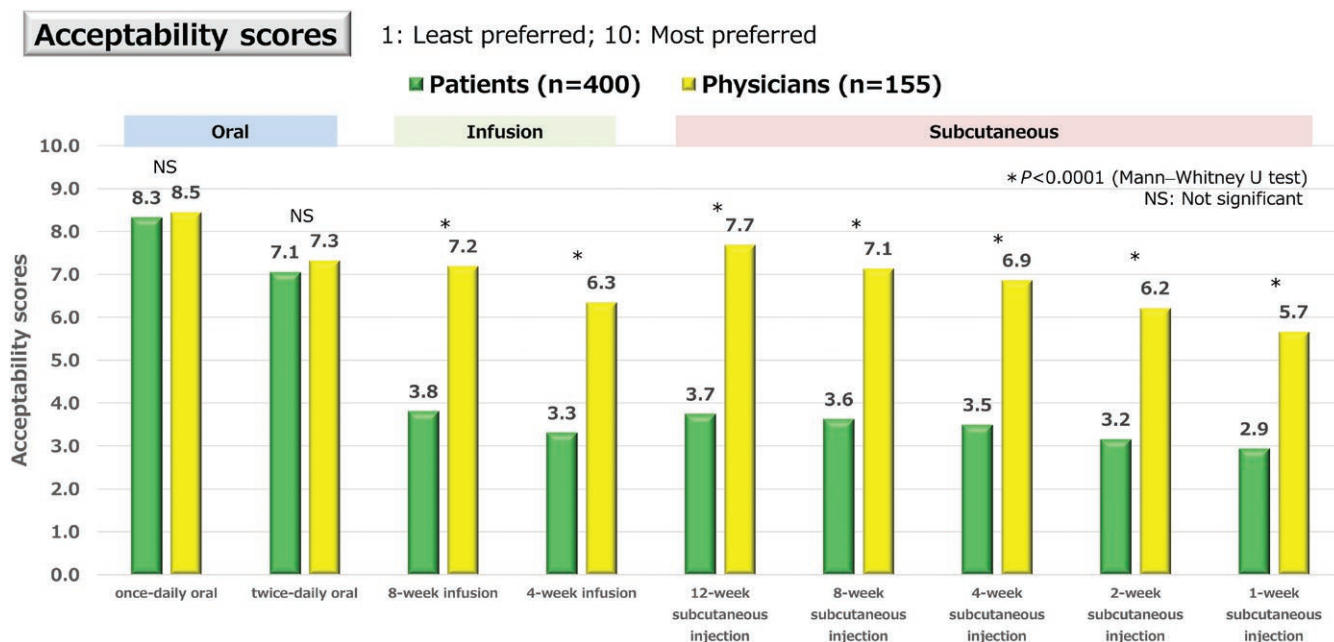


Figure 3. Preference for administration methods. The 10-level acceptability scores for administration methods. Acceptability scores were higher for once-daily oral administration, with significant differences between other administration methods in both patients and physicians ($P < .0001$). Patients' scores were significantly lower than those of physicians' scores for intravenous and subcutaneous methods of administration ($P < .0001$).

oral formulation remained the most preferred choice with the highest score, which is consistent with the results of a previous survey conducted in Japan.⁴⁰ We also evaluated by severity of symptoms, but no notable differences were observed. Additionally, this survey evaluated physicians' preferences for drug administration methods. We believe that this is the first study to explore physicians' preferences of drug administration for advanced therapies in IBD. The acceptability scores for oral administration were comparable between the 2 groups; however, patients' assigned significantly lower scores for intravenous and subcutaneous routes than did physicians. Furthermore, compared with patients, physicians about the most preferred method of administration were significantly less likely to prefer oral administration, suggesting that

physicians may overestimate the convenience of intravenous and subcutaneous formulations. Subcutaneous injections and infusions are also accepted by patients in daily practice, and we assume that physicians consider subcutaneous injections and infusions to be more convenient because of the longer dosing intervals than oral agents. Though the drug selection is based not only on the method of administration, but it is important to carefully consider patients' opinions regarding the acceptability of the administration method when implementing SDM.

This study had several limitations. First, online-based survey may have introduced the possibility of a biased population. Specifically, there is concern that the elderly and other patient groups that are not comfortable with digital

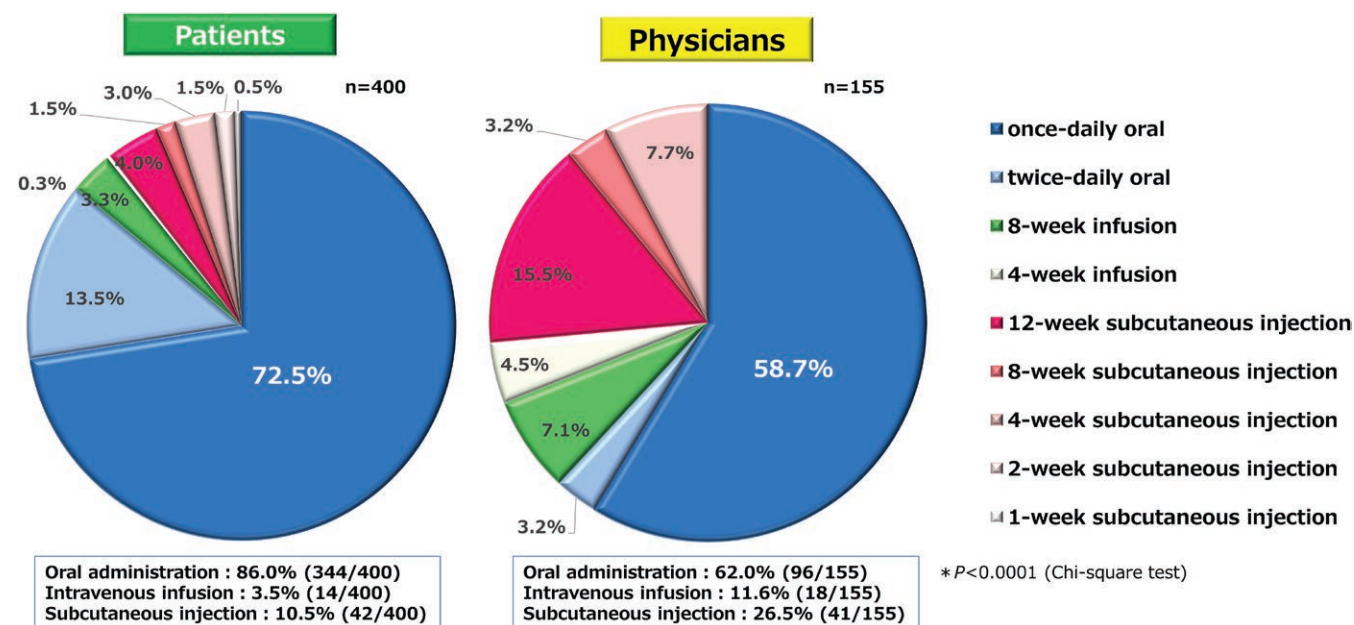


Figure 4. Most preferred method of administration. Compared with patients, physicians were significantly less likely to consider oral administration as the most preferred administration method ($P < .0001$).

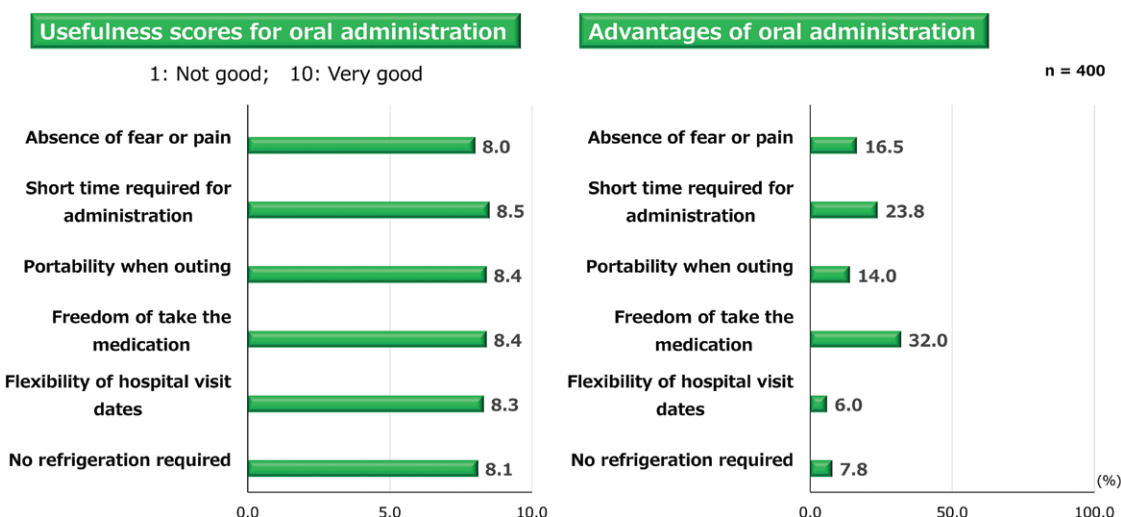


Figure 5. Patients' perspective of usefulness of oral administration

devices may be excluded. However, the average age of the patients in this study was 53.1 years, and there were no trends that elderly patients were specifically excluded from the study compared to the general population. Although the proportion of male patients was relatively high, this aligns closely with the general sex ratio and age distribution of patients with IBD in Japan and Asian countries.⁴²⁻⁴⁵ In addition, the regions of residence of the respondents were less biased, suggesting that geographic bias was relatively small. Second, because this was an Internet-based survey, there may be limitations in response accuracy. However, Kelstrup et al. after matching 197 patients' Internet survey responses with their actual medical records, they report that Internet surveys can be conducted with a high degree of reliability.⁴⁶ Furthermore, similar methodologies have been employed successfully in several other studies.^{2,39,40,47} Third, this survey was conducted only in Japan, and the

results may be different in other countries. Although this is a valid concern, many sub-analyses of international studies to date have not shown that findings in Japan are significantly different from those in other countries.^{24,26,30,31} Although these ethnic variations may impact future surveys, we believe that the results of the present study are informative.

In conclusion, our online survey results highlighted both similarities and differences in the perspectives of patients with IBD and physicians treating IBD in strategizing treatment decisions and their preferences for administration methods. Overall, patients and physicians aligned on several aspects of drug selection, although physicians emphasized their previous experience with the drugs. Both patients and physicians found oral formulations to be a convenient treatment option; however, physicians may overestimate the convenience of intravenous and subcutaneous formulations over

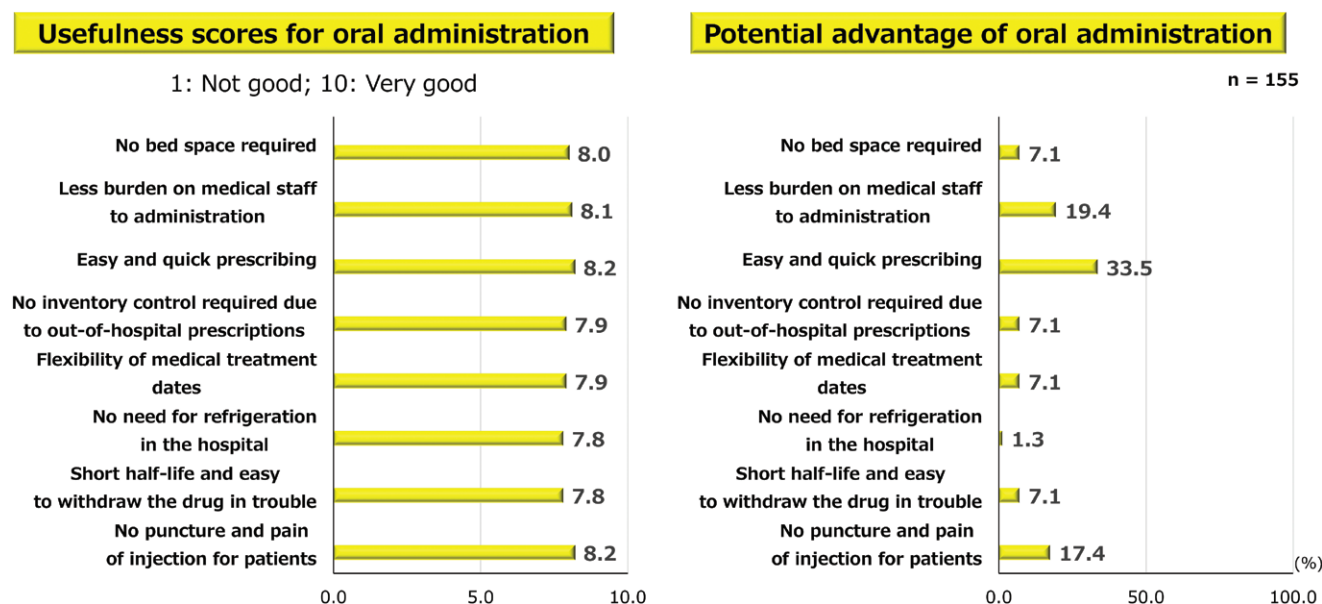


Figure 6. Physicians' perspective of usefulness of oral administration

patients. These findings suggest that implementing SDM that incorporates the needs and preferences of IBD patients for selecting advanced therapies would improve patient satisfaction and adherence.

Supplementary Data

Supplementary data are available at *Crohn's & Colitis* 360 online.

Acknowledgments

This survey was planned and supported by EA Pharma Co. Ltd. (Tokyo, Japan) and conducted by Cross Marketing Co. Ltd. (Tokyo, Japan).

Author Contributions

F.H. and T.M. drafted the manuscript and reviewed relevant literature. M.U. designed the survey and drafted the manuscript. K.I., Y.G., Y.F., T.K., M.O., and T.H. designed the study. M.H. participated in the data analysis. All the authors have read and approved the final version of the manuscript.

Funding

This work was supported by EA Pharma Co. Ltd.

Conflicts of Interest

F.H. and T.M.: Lecture fee and consultant fee; EA Pharma Co., Ltd. K.I., Y.G., Y.F., T.K., M.O., T.H., M.H., and M.U.: EA Pharma Co. Ltd.

Data Availability

Data not publicly available. The data used and analyzed in this study are available from the corresponding author upon reasonable request.

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