〈研究ノート〉

Gastroenterologists' Perceptions and Practice Regarding Shared Decision-making for Patients with Crohn's Disease

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クローン病患者を診療する消化器専門医の Shared Decision Making の認識と実践

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〈Abstract〉

Objectives: This study examined the perceptions and practice of gastroenterologists regarding shared decision-making (SDM) in patients treated for Crohn's disease. It then explored factors that could affect this practice.

Methods: In Japan, from December 2018 to January 2019, we conducted a nationwide online survey of gastroenterologists who had treated patients with Crohn's disease. We asked about the recognition, benefits, barriers, methods, and important aspects of SDM-related treatment. We used a chi-square or Fisher's exact test, and multiple logistic regression, to analyze factors associated with practicing SDM.

Results: We analyzed data on 93 gastroenterologists, of whom 58% were familiar with SDM and 52% practiced it. Respondents cited either a lack of time (91%) or tools (51%) as the main barriers to conducting SDM. Actual practice was related to the surveyed gastroenterologists' views concerning what aspects were important in treatment decisions. The multiple logistic regression analyses identified that the surveyed gastroenterologists regarded patients' preferences or values as the most relevant factor in treatment-related SDM.

Conclusions: Over half of the surveyed gastroenterologists were familiar with SDM, and most used it when making treatment decisions. Views regarding what was important in treatment decisions affected actual practice of SDM. Healthcare professionals should examine the time required for SDM and develop useful tools to promote its practice.

〈要旨〉

目的：本研究は，クローン病患者を診療する日本の消化器専門医の shared decision-making（SDM）の認識と実践状況を明らかにし，SDM 実践の関連要因について検討することを目的とした。

方法：クローン病患者の診療経験のある日本在住の消化器専門医を対象に 2018 年 12 月から 2019 年 1 月にかけて全国規模のオンライン調査を実施した。調査内容は SDM の認知度，SDM とその効果に対する認識，SDM 実践の障壁，治療法の決め方，治療法の決定に関わる際に重視するものとした。SDM 実践に関連する要因について X^2 検定または Fisher の正確確率検定，多重ロジスティック回帰分析を用いて分析を行った。

結果：93 名の分析対象者のうち，SDM について「知っている」と回答した者が 58% であり，SDM を実践していた者は 52% であった。SDM 実践の障壁として「時間の不足」（91%）と「ツールの不足」（51%）が挙げられた。SDM の実践は治療法の決定の際に医師が何を重視するかに関連しており，多重ロジスティック回帰分析の結果，「患者の希望・選好・価値観」を重視するか否かが最大の関連要因として特定された。

結論：クローン病患者を診療する消化器専門医の約半数が SDM を知っており，SDM を用いて治療を決めていた。

医師が治療の決定に関わる際に重視するものがSDMの実践に関連していた。SDMを促進するには，実践にかかる時間について検討するとともにSDMを具現化するための有用なツールを開発する必要性が示唆された。

Key words
Crohn's disease　クローン病
gastroenterologist　消化器専門医
shared decision-making　シェアードディシジョンメイキング

Ⅰ. Introduction

Crohn's disease (CD) is an intractable inflammatory bowel disease (IBD) of unknown etiology. It is thought to result from a complex interplay among genetic susceptibility, environmental factors, and altered gut microbiota that leads to dysregulated innate and adaptive immune responses[1,2]. Most patients develop the condition at around 20 years old and require lifelong medical treatment, going through periods of relapse and remission. The prevalence of CD has increased steadily in most regions worldwide[2], and in 2016, the number of Japanese patients with CD was estimated above 40,000[3].

Management of CD typically involves starting patients on aminosalicylates, steroids, or thiopurine, with escalation to other treatments only after these options fail (i.e., step-up therapy). A novel "treat-to–target" strategy was recently proposed; this necessitates regular assessment of disease activity by objective clinical and biological outcome measures, with treatment adjustments made if needed. The approach facilitates earlier use of immunosuppression or combination therapy with biologics in high-risk patients[1,4]. Coupled with these changes in management, therapeutic options for CD have expanded; thus, patients and healthcare professionals may have difficulty deciding on optimal treatments. Such choices could be on whether to use an aggressive top-down approach with biologics or use conventional step-up therapy.

Both patients' and healthcare professionals' preferences affect treatment decisions[5,6], and when coupled with the range of available options, treatment decisions for CD are ideally suited to shared decision-making (SDM). SDM is "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences"[7]. The SDM concept has permeated mainstream clinical practice in Europe and North America, with several decision aids now available to structure its application when deciding on treatment for patients with IBD[8,9]. An investigation of U.S. gastroenterologists found that 80% had a positive view of SDM for patients with CD, yet it also showed only 12% actually practiced SDM[10].

In a survey of Japanese patients with IBD, most respondents felt SDM was very important[11]. A clear correlation was also found between the extent to which patients and their doctors agreed on decision-sharing and overall patient satisfaction with treatment[12]. Despite this, we were unable to find any research on SDM or the decision methods used by gastroenterologists in Japan who treat patients with CD. Factors affecting Japanese gastroenterologists' use of each decision-making method are also unknown. Charles et al.[13] suggested four key characteristics of SDM: (1) at least two participants, (2) both parties share information, (3) both parties take steps to build a consensus about the preferred treatment, and (4) agreement is reached on the treatment choice. If a doctor does not actively seek to engage in SDM, a patient's wishes could be treated as irrelevant,

which may reduce the standard of care.

SDM should become increasingly central to treatment-related decisions given the growing prevalence of CD in Japan and advances in both new medications and treatment approaches. To add to existing research on patient perceptions, we therefore sought to investigate SDM-related perceptions and practice of gastroenterologists in treating patients with CD, and to explore the factors that affect such practice.

Ⅱ. Methods

1. Study design and participants

We conducted a nationwide online survey of gastroenterologists in Japan who had managed patients with CD. The survey was conducted from December 2018 to January 2019 by the Nippon Research Center, a specialist provider of online surveys, and accessing a panel of registered physicians. Using this panel introduced the risk of preferentially including respondents from specific medical institutions or who were more active among physicians in sharing information. Such risks may lead to biased results regarding gastroenterologists' perceptions and the practice of SDM. To mitigate this, we generated a candidate list of gastroenterologists who met certain requirements. First, we performed an exhaustive survey of 3,238 large-scale domestic hospitals that, based on published results[14], provided medical treatment for CD (≥10 patients hospitalized annually). We then confirmed whether each facility had a practicing gastroenterologist and added these facilities and gastroenterologists to our candidate list. We also extracted candidates from a list of doctors who treated patients in Japan, as recorded on the Crohn's and Colitis Foundation of Japan website[15]. The final list included 247 facilities (223 hospitals and 24 clinics) comprising 647 candidate participants (1–13 per facility). We set a maximum of three candidates per facility to avoid bias toward the practice results at specific institutions. We then contacted the gastroenterologists by telephone using information provided on each facility's website. Those who showed intent to participate were emailed a link/URL for accessing the survey. We collected and analyzed the results upon survey completion.

2. Questionnaire

The survey questionnaire was created with reference to that developed by Siegel et al.[10] and comprised 17 items among seven modules: (1) gastroenterologists' characteristics, (2) recognition of the term "shared decision-making," (3) agreement with SDM and its benefits, (4) barriers to practicing SDM, (5) treatment decisions deemed appropriate for SDM, (6) preferred decision-making approach when treating CD, and (7) what gastroenterologists viewed as important when they were involved in treatment decisions for CD.

3. Statistical analysis

Descriptive statistics are shown as a number (percentage) for categorical variables such as respondents' characteristics and perceptions of SDM and decision-making methods. We used a chi-square or Fisher's exact test to analyze the factors related to practicing SDM. We also used multiple logistic regression analysis (forced entry) to explore three independent variables that could affect SDM: evidence about treatment risks, evidence about treatment benefits, and patient preferences or values. All analyses were performed using IBM SPSS Version 25.0 for Windows (IBM Corp., Armonk, NY, USA), with $p < 0.05$ considered statistically significant.

4. Ethical considerations

This study was approved by the ethics committee of Mukogawa Women's University (No. 18–23). The first page of the online survey explained the study's purpose, methods, data handling (e.g., personal information), and contact details to the participants. Only participants who

read the document and clicked "I agree" could then access the response pages.

Ⅲ. Results

1. Gastroenterologists' characteristics

Of the 95 gastroenterologists who completed the survey, two were excluded for not answering questions on recognition of the term "SDM" or on methods used when making treatment-related decisions. Consequently, 93 respondents were included in the final analyses (Table 1).

2. Perception of SDM

Of the surveyed gastroenterologists, 58% were familiar with the term "SDM" (9% extremely familiar, 11% familiar, and 38% somewhat familiar), whereas 42% were not familiar (38% not at all familiar and 4% not familiar) (Table 2).

The participants had a largely positive perception of SDM and its benefits, with more than 90% agreeing that SDM leads to increased patient satisfaction (58% strongly agreed and 36% somewhat agreed). Additionally, 85% agreed that using SDM could lead to better clinical outcomes (34% strongly agreed and 51% somewhat agreed), and over 90% disagreed that patients were unqualified to participate in treatment decisions (86% strongly disagreed and 11% somewhat disagreed). In contrast, fewer respondents (67%) disagreed with the statement that SDM was not worth the time it takes (19% strongly disagreed and 48% somewhat disagreed) (Figure 1).

Lack of time (91%) was the most commonly reported barrier to practicing SDM. All other perceived barriers were mentioned, including the lack of decision aids or tools to assist with SDM (51%), belief there was insufficient evidence that SDM would improve clinical outcomes (33%), lack of reimbursement (28%), and lack of space in one's office or other practice setting (24%) (Table 2).

The respondents indicated that SDM was appropriate in many situations, with most agreeing it was useful when selecting a course of treatment that may have significant risks and benefits (94%) and in deciding on selective surgical procedures

Table 1　Surveyed gastroenterologists' characteristics

Variables		N = 93
Gender	n	(%)
Male	83	(89)
Female	10	(11)
Age		
≤ 39 years	15	(16)
40–49 years	35	(38)
50–59 years	33	(35)
60–69 years	9	(10)
≥ 70 years	1	(1)
Years' experience treating patients with Crohn's disease		
≤ 9 years	23	(25)
10–19 years	32	(34)
≥ 20 years	38	(41)
No. patients with Crohn's disease seen in an average month		
≤ 10 patients	28	(30)
11–25 patients	26	(28)
26–75 patients	25	(27)
≥ 76 patients	14	(15)
Main type of medical facility		
Specialist hospital	34	(37)
University hospital	17	(18)
General hospital	31	(33)
Clinics	11	(12)

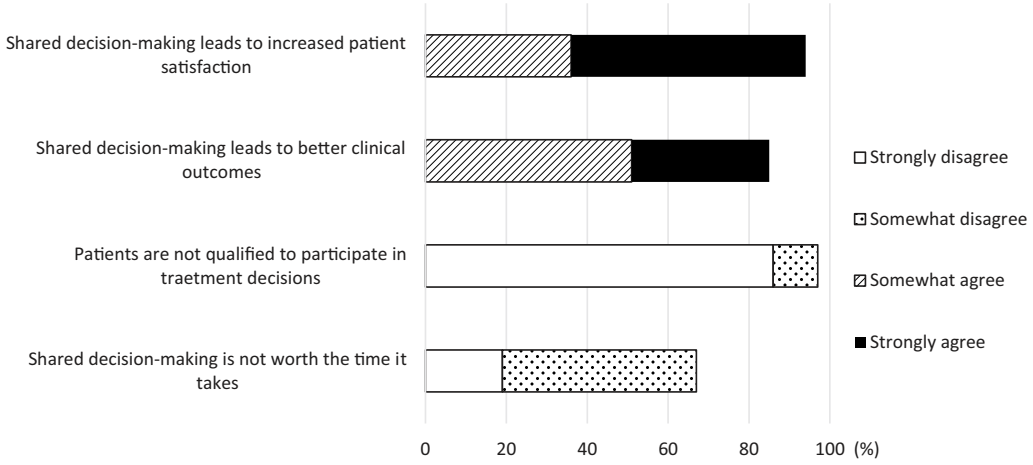

Figure 1 Surveyed gastroenterologists' perceptions of shared decision-making benefits

(80%) (Table 2).

3. SDM practice

About half (52%) of the respondents reported they decided on actual treatment together with their patients irrespective of the patients' preference toward or interest in decision-making (i.e., the SDM group). However, 39% reported they decided on treatment with a patient only if the patient showed an interest in participating in the decision-making. Meanwhile, 10% reported the decision was to be made by the gastroenterologist alone or in consultation with other healthcare professionals. Evidence about treatment benefits (77%) and reported disease severity (73%) were the main factors considered important when making treatment-related decisions. Evidence about

Table 2 Surveyed gastroenterologists' perceptions of shared decision-making

Variables	N = 93	
Recognition of SDM term	n	(%)
Not at all familiar	35	(38)
Not familiar	4	(4)
Somewhat familiar	35	(38)
Familiar	11	(11)
Extremely familiar	8	(9)
The key barrier to practicing SDM (select all that apply)		
Lack of time	85	(91)
Lack of decision aids or tools	47	(51)
Insufficient evidence that SDM will improve clinical outcomes	31	(33)
Lack of reimbursement	26	(28)
Lack of space in their office or practice setting	22	(24)
Insufficient evidence that SDM will increase patient satisfaction	12	(13)
Fear of legal liability	5	(5)
What types of decisions that are appropriate for SDM (select all that apply)		
Selecting a course of treatment that may have significant risks and benefits	87	(94)
Deciding on selective surgical procedures	74	(80)
Prescribing treatment for a chronic disease with several relatively low risk treatment options	45	(48)
Making critical, consequential decisions in life threatening circumstances when there are several options	43	(46)
Routine, low risk medical interventions	27	(29)
Urgent, life-saving intervention	17	(18)

treatment risks (49%), patient preferences or values (46%), and patient characteristics and backgrounds (30%) were other important considerations.

4．Factors affecting the practice of SDM

The chi-square test results showed the type of medical facility at which the respondent worked ($X^2 = 8.226$, degrees of freedom [df] = 3, p = 0.042) was the main characteristic associated with SDM practice. Gastroenterologists working in universities or specialized medical facilities tended to respond that SDM informed their treatment decisions. Additionally, those who regarded evidence about treatment risks or methods as important did not tend to make SDM-informed treatment decisions ($X^2 = 6.682$, df = 1, p = 0.010; $X^2 = 9.195$, df = 1, p = 0.002), whereas those who regarded patient preferences or values as important did tend to make SDM-informed treatment decisions ($X^2 = 9.322$, df = 1, p = 0.002) (Table 3).

Finally, Table 4 details the multiple logistic regression results. Whether gastroenterologists regarded patient preferences or values as important in treatment-related decision-making (odds ratio = 3.04; 95% confidence interval = 1.21–7.64; p = 0.018) was the most strongly predictive factor of practicing SDM.

Table 3 Factors associated with methods used for treatment-related decisions

	SDM	non-SDM	Total	X^2	df	p
n (%)	48 (52)	45 (48)	93			
Gender				0.316	1	0.412[b]
Male	42 (51)	41 (49)	83			
Female	6 (60)	4 (40)	10			
Age				3.046	1	0.081[a]
<50 years	30 (60)	20 (40)	50			
≥ 50 years	18 (42)	25 (58)	43			
Years' experience treating patients with Crohn's disease				1.216	1	0.270[a]
<20 years	31 (56)	24 (44)	55			
≥ 20 years	17 (45)	21 (55)	38			
No. patients with Crohn's disease seen in an average month				0.134	1	0.714[a]
<25 patients	27 (50)		54			
≥ 26 patients	21 (54)	18 (46)	39			
Main type of medical facility				8.226	3	0.042[a]
Specialist hospital	19 (56)	15 (44)	34			
University hospital	13 (77)	4 (23)	17			
General hospital	13 (42)	18 (58)	31			
Clinics	3 (27)	8 (73)	11			
Recognition of SDM				2.768	2	0.251[a]
Extremely familiar/ familiar	13 (68)	6 (32)	19			
Somewhat familiar	16 (46)	19 (54)	35			
Not at all familiar/ not familiar	19 (49)	20 (51)	39			
What gastroenterologists view as important in treatment decision-making						
Evidence about the treatment risks	17 (38)	28 (62)	45	6.682	1	0.010[a]
Evidence about the treatment benefits	37 (52)	34 (48)	71	0.030	1	0.862[a]
Severity of disease	37 (56)	29 (44)	66	1.801	1	0.180[a]
Treatment methods	2 (14)	12 (86)	14	9.195	1	0.002[a]
Treatment costs	5 (71)	2 (29)	7	1.190	1	0.245[b]
Patient's characteristics and backgrounds	10 (37)	17 (63)	27	3.237	1	0.072[a]
Patient's preferences or values	29 (69)	13 (31)	42	9.322	1	0.002[a]

Data are presented as n (%).
Shared decision-making (SDM) indicates that healthcare professionals decide on treatments with all patients regardless of the patients' interest in that process.
[a] Chi-square test; [b] Fisher's exact test

Table 4 Factors affecting surveyed gastroenterologists' use of shared decision-making

	OR	95% CI	*p* value*
What gastroenterologists view as important in treatment decision-making (n = 93)			
Evidence about the treatment risks (reference do not view as important)	0.45	0.18–1.11	0.084
Evidence about the treatment benefits (reference do not view as important)	1.46	0.52–4.07	0.474
Patient's preferences or values (reference do not view as important)	3.04	1.21–7.64	0.018

Abbreviations: OR, odds ratio; CI, confidence interval; SDM, shared decision-making. *Multiple logistic regression analysis (forced entry) was performed whether or not SDM was used as a dependent variable, and the above three factors were independent variables.

Ⅳ. Discussion

This was the first nationwide survey in Japan to detail gastroenterologists' perceptions and practice regarding SDM. In a U.S. study, 77% of gastroenterologists were familiar with SDM[10]. In the current study, 58% were familiar with it and 38% were not at all familiar with it, indicating SDM has not fully permeated Japanese clinical practice. The SDM concept was introduced in medicine in the 1980s, at which time it drew upon and deepened the principles of patient-centered care[16]. In North America, SDM is well-established, with practical models having been developed and revised for how to implement it in routine clinical settings[17–19]. The study and practice of SDM in Japan, however, is in its relative infancy, with the low recognition in the current study confirming this nascent level.

In our survey results, most gastroenterologists viewed SDM and its benefits positively, similar to the results in a U.S.-based survey[10]. In both surveys, selecting a course of treatment that may have significant risks and benefits (94% in our survey, 87% in a U.S.-based survey[10]) was the decision considered most appropriate for SDM. Whitney et al.[20] demonstrated a model that placed medical decisions along two axes—risk and certainty—with SDM being most appropriate in uncertain situations in which there were two or more clinically feasible alternatives. Thus, SDM is compatible with selecting a course of treatment that may have substantial risks and benefits. Biologics provide an example for which viable treatment choices (e.g., infliximab, adalimumab, and ustekinumab) exist, and for which the expected high efficacy must be weighed against increased risks of, for example, lymphoma or serious infection, that endanger the patient's life. Use of biologics for treating CD is increasing in Japan, with approximately 50%–60% of patients receiving them[21]. Ensuring patient involvement via SDM when making treatment-related decisions should therefore play an increasingly important role in the future.

Gastroenterologists in the United States perceived lack of time (74%), lack of reimbursement (70%), and lack of decision aids or tools (51%) as the main barriers to SDM in clinical practice[10]. Similarly, we showed gastroenterologists in Japan perceived lack of time (91%) and lack of decision aids or tools (51%) as the main barriers. Of note is the higher percentage of Japanese gastroenterologists' citing lack of time as an issue. This is also consistent with a systematic review that found lack of time was the most common barrier to healthcare professionals' using SDM[22]. Another systematic review, on the utility of decision aids, showed they added only a median 2.6 minutes to the length of a typical consultation[23]. We assert that many of the barriers healthcare professionals perceive might be myths in need of dispelling[24]. Further research is required to evaluate the time needed to practice SDM and to develop validated aids or tools for conducting SDM in Japan.

In our study, just over half (52%) of the surveyed gastroenterologists reported basing their actual treatment decisions on SDM. A previous survey showed only 15% of general physicians at clinics in Tokyo practiced SDM[25]. Compared with those results, our study may indicate that gastroenterologists may practice SDM more actively than other physicians. Gastroenterologists' work settings were also relevant to use of SDM, with those working in universities or specialized medical facilities tending to report SDM-informed treatment decisions. Those working in general hospitals or clinics, however, tended to respond that SDM did not inform their treatment decisions. Kuga et al.[25] suggested that doctors who examined patients from a generalist perspective tended to unilaterally decide on treatment more often than specialists who examined patients with specific diseases. This may account for the difference in use of SDM between the university or specialized medical facilities and the general hospitals or clinics.

The gastroenterologists in our study regarded evidence about treatment risks, treatment methods, and patient preferences or values as important toward treatment-related decisions and strongly related with the practice of SDM. Those who placed importance on evidence about treatment risks or methods largely tended to not practice SDM. Additionally, they saw clinically appropriate treatment decisions as achievable without SDM because evidence about treatment risks and methods is available in articles and guidelines. Gastroenterologists who regarded patients' preferences or values as important, however, largely tended to practice SDM. Given that only the patient can communicate these preferences or values, this belief may lead to better and more active communication with patients, and thus result in SDM.

Several limitations should be noted when interpreting the results of this study. All data were collected via self-reported questionnaires, which can affect data reliability. Respondents may also have been more likely to have an interest in SDM or patient-centered medicine, which could affect their positive views regarding SDM and its benefits. Nevertheless, we obtained informative responses from a relatively large number of gastroenterologists in Japan, including those from specialized, university, and general hospitals. This latter point improves the potential generalizability of our data.

The concept of SDM has recently expanded beyond the physician–patient dyad to include the interprofessional healthcare team[26]. Further research is therefore still needed to examine perceptions of SDM among other healthcare professionals involved in the treatment of patients with CD, with the aim of promoting an interprofessional approach to SDM.

In conclusion, we examined the perceptions and practices of gastroenterologists in Japan regarding SDM for patients with CD. Our survey showed SDM has yet to be fully applied among this physician population, despite most practitioners viewing it positively and about half using it routinely. The results also showed that the work setting and the views of gastroenterologists concerning what aspects are important in treatment decisions affected the practice of SDM.

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