Factors of Self-Care Agency in Patients with Inflammatory Bowel Disease in Japan

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Abstract

Introduction: Currently, no self-care measurement tool specific to inflammatory bowel disease (IBD) exists in Japan. The Instrument for Diabetes Self-care Agency (IDSCA) is a reliable and valid self-care measurement tool for patients with diabetes. Factors affecting self-care ability assessed by IDSCA appear to meet the requirements for patients with IBD. Therefore, we created a self-care ability measurement tool adapted from IDSCA as an original draft for the Instrument for IBD Self-care Agency and extracted factors and items required to measure the self-care ability of patients with IBD. ***Methods:*** An anonymous questionnaire survey was distributed among 226 patients. Exploratory factor analysis examined the relationship of factors from multiple perspectives, identified factors based on their content, and confirmed their internal consistency. Statistical analyses were performed using JMP® 14.0.0. ***Results:*** Five factors with 23 items were extracted from the IDSCA, including ability to build a human support system, ability to acquire knowledge, ability to maintain self-care, ability to self-manage, and ability to self-assess. Cronbach's alpha was 0.765–0.861 for each factor and 0.904 for the entire scale. ***Conclusion:*** We could identify the self-care agencies of patients with IBD, including 5 factors and 23 items. Focusing on these self-care factors may provide critical information to guide nurses' self-care interventions.

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Introduction

Inflammatory bowel disease (IBD) is characterized by a nonspecific intestinal inflammation caused by mucosal damage to the digestive tract. It manifests from ulcerative colitis (UC) and Crohn's disease (CD). With a high incidence among individuals in late adolescence and their 20s, the number of patients in 2014 exceeded 220,000 for UC and 70,000 for CD. The number of cases is increasing in Japan [1]. Globally, the number of patients with IBD has been increasing in developed and developing countries [2].

The goal of IBD treatment is clinical remission and maintenance of remission without using steroid followed by endoscopic remission [3]. IBD causes digestive symptoms; in chronic IBD cases with repeated flare-ups and remissions, long-term restrictions on behavior and diet are required, affecting school, employment, and

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social life [4, 5]. The self-care needs of patients with IBD can be easily misunderstood because they are difficult to distinguish from people without the disease [6]. Taking self-care initiative can improve patients' quality of life [7, 8]. Therefore, by focusing on the self-care of patients with IBD, nurses can facilitate self-care according to their treatment goals and medical conditions.

Evidence for self-care in patients with IBD has been accumulated from the viewpoint of drug therapy, diet therapy, exercise therapy, and psychotherapy [9]. As IBD onsets at a young age, it can affect psychosocial aspects and symptom control [10]. Individual patients can demonstrate self-care abilities during specific circumstances, such as eating [11], detecting and coping with symptoms [12], and daily working [13]. Moreover, several studies have documented nurses' perspectives on assessing the self-care needs [14, 15] and practices [16] of patients. However, because of the diversity of IBD pathologies and lifestyle factors, self-care interventions for patients with IBD in health care settings should focus on promoting patients' potential self-care abilities without relying on specific situations. The comparison of factors that influence self-care by patients with IBD in Japan with those in regions with nurses who specialize in IBD (e.g., Scandinavia, Europe, and the USA) cannot be performed because of the differences in factors that affect self-care, such as region and culture. Therefore, objective review of self-care skills of patients with IBD in Japan using measurement tools can help identify nursing assistance that facilitates self-care.

Currently, Japan has no IBD-specific self-care agency measurement tools. Conversely, tools have been developed overseas that comprise factors [17]. However, there are differences in preferences between Japan and other countries, as indicated by the items included in a previously reported self-care ability measurement tool, such as snuff cigarettes, which was excluded from Japanese tools. In addition, differences in environmental factors have been observed in the health care delivery systems. For example, nurses specializing in IBD, in countries throughout Northern Europe, have discretionary authority for care, which include making phone calls [18], whereas nurses in Japan have no such discretionary authority. Therefore, a tool to assess the self-care agency of patients with IBD according to their treatment and life background in Japan is warranted.

The importance of self-care has been reported in diabetes, and the Instrument of Diabetes Self-Care Agency (IDSCA) comprises 8 factors and 40 items [19, 20]. Although disease characteristics differ between diabetes and IBD, medical professionals and patients work together in both diseases with the support of others around them and live with their illnesses. Previously developed tools can identify and evaluate distress in patients with IBD by analyzing the differences between IBD and diabetes [21, 22]. In addition, it is challenging to extract self-care abilities directly from patients with IBD because of their pathology and diversity as previous studies have focused on self-care in patients with IBD [17, 23]. In Scandinavia, there are nurses specializing in IBD, but in Japan there are none. Therefore, the identification of self-care agency unique to Japanese patients with IBD would help nurses support self-care in accordance with the Japanese medical background. Accordingly, factors of self-care agency specific to patients with IBD could be extracted from the IDSCA's factors of self-care ability. This study aimed to develop a draft of an IBD self-care agency assessment item modified by considering the characteristics of patients with IBD and extract the factors that constitute the self-care agency of patients with IBD from the IDSCA.

Materials and Methods

Self-Care Agency
Self-care comprises independent and intentional activities based on decision-making, aiming to improve patients' well-being and health [19, 24–26]. This study defined self-care agency as an individual's ability to perform these various activities.

Participants and Data Collection
We included patients with IBD diagnosed with UC or CD who attended Clinic A and were aged ≥18 years at the time of giving consent. As this was a self-administered questionnaire survey, patients with cognitive impairment or psychiatric disorders were excluded.

A ≥5-time greater sample size than the number of items is generally necessary to validate exploratory factor analysis. As IDSCA has 40 items for self-care ability, a sample size of ~200 participants would be necessary. However, considering the possibly of invalid responses, we set the sample size to 250.

The participants were explained the data collection method in writing and orally during the outpatient consultation before filling the questionnaire during the waiting time in the facility. The questionnaires were dropped in a collection box in the facility. If no participant could complete the survey during this time, they put their questionnaire in an envelope and sent it via mail. The data were collected from August 29 to October 5, 2019.

Instrument
The IDSCA comprises 40 items with eight factors: ability to acquire knowledge, ability to cope with stress, ability to make the most of the support available, monitoring ability, application or adjustment ability, motivation to self-manage, ability to self-manage, and body self-awareness [19]. There were 40 items, and the IDSCA was modified based on IBD characteristics to include IBD-specific assessment items (Table 1). During

Table 1. Modification items

IDSCA		Items after modification
Factor	Item	
Ability to acquire knowledge	You are aware about the relationship between blood sugar levels and eating	You are aware about the relationship between inflammation and eating
	You are aware about the relationship between exercise and blood sugar levels	You are aware about the relationship between the stress and inflammation
	You are aware of complications of diabetes	You are aware of the complications of IBD
	You are aware that blood sugar levels can be high without symptoms	You are aware that inflammation (CRP) can be high without symptoms
	You know that colds and other health problems can affect blood sugar levels	You know that colds and other health problems can affect inflammation
Ability to cope with stress	You always feel tense about properly controlling your diabetes	You always feel tense about properly controlling your IBD
	You cannot sleep at night when you think about diabetes	You cannot sleep at night when you think about IBD
Ability to make the most of the support available	You have someone who is the first to notice when your body is not feeling well (e.g., low blood sugar)	You have someone who is the first to notice when your body is not feeling well (e.g., diarrhea, abdominal pain)
Monitoring ability	You judge your physical condition, diet, and exercise by checking your blood sugar levels	You judge your physical condition, diet, and exercise by checking your symptoms
	You can predict if your blood sugar is going to be high	You can predict if the CRP levels (a measure of inflammation) in your blood draw are going to be high
	You can predict whether you have low blood sugar	You can predict whether you occur symptoms of inflammation (diarrhea, fever, bloody stool, etc.)
Motivation to self-manage	You are interested in diabetes	You are interested in IBD
Body self-awareness	You feel the importance and risks of diabetes acutely	You feel the importance and risks of IBD acutely

IDSCA, Instrument of Diabetes Self-Care Agency; IBD, inflammatory bowel disease; CRP, C-reactive protein.

modification, we reviewed and revised the content of the items with the supervision of an IDSCA developer, a well-experienced IBD nurse, and IBD specialist to ensure content validity, because self-care in IBD is diverse, given the disease characteristics.

Questionnaire for Patients

The basic attributes were age, sex, occupation, last education, availability of assistance, disease name (CD or UC), disease duration, disease type, surgery history, stoma presence, hospitalization frequency, anal lesion presence, current treatment, hospital visit frequency, and dietary adjustment degree. The 40 items of the eight factors of the self-care agency assessment for patients with IBD based on the IDSCA were rated on a 6-point Likert scale (0, strongly disagree; 1, disagree; 2, less agree; 3, somewhat agree; 4, agree; and 5, strongly agree). The participants chose the number that was best represented their experience.

Statistical Analysis

Ceiling and floor effects were checked using descriptive statistics, and applicable items were excluded. To eliminate the possibility of items measuring the same content, we excluded items with correlation coefficients of ≥0.8.

The factors were analyzed with maximum likelihood Promax rotation. We conducted an exploratory factor analysis without specifying the number of factors and excluded items with commonality estimates <0.1 or >1.0. Based on the screen plot results, the components were reduced by factor analysis based on a factor loading of 0.40. The number of factors was based on the slope and eigenvalues of the scree plot; however, the number of factors whose meaning could be interpreted was adopted. We named the factors according to their contents and extracted the factors that constitute the self-care agency of patients with IBD.

Table 2. Basic attributes of the participants

Attribute	n	%
Gender		
Men	149	65.9
Women	77	34.1
Age (mean±SD), years	38.8±10.7 (18–72)	
Diagnosis		
CD	153	67.7
UC	72	31.9
Nonresponse	1	0.4
Disease duration (mean±SD), years	13.4±8.1 (1–43)	
Treatment (multiple answers)		
Biologics	178	78.8
Immunomodulators	42	18.6
5-aminosalicylic acid	35	15.5
Intestinal and stomach medications	25	11.1
Steroids	15	6.6
Elemental diet	17	7.5
Chinese herbal medicine	12	5.3
Home central venous hyperalimentation	5	2.2
Semidigestible form of nutrition	2	0.9
Acupuncture and moxibustion therapy	2	0.9
No treatment	1	0.4
Cytapheresis therapy	0	0
Other	7	3.1
Nonresponse	8	3.5
Frequency of visits		
Every 3 months	2	0.9
Every 2 months	145	64.2
Every 1 month	64	28.3
Twice a month	11	4.9
At least thrice a month	0	0
Irregular	2	0.9
Nonresponse	2	0.9
Occupation		
Full-time employee	128	56.6
Part-time employee	21	9.3
Housewife/househusband	19	8.4
Independent business	15	6.6
Student	13	5.8
Unemployed	12	5.3
Technical job	7	3.1
Other	10	4.4
Nonresponse	1	0.4
Last education		
High-school junior	7	3.1
High school	47	20.8
Vocational school	30	13.3
University	113	50
Graduate school	21	9.3
Other	5	2.2
Nonresponse	3	1.3

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Table 2 (continued)

Attribute	n	%
Availability of assistance (multiple answers)		
Spouse	116	51.3
Mother	116	51.3
Father	59	26.1
Sibling	34	15
Child	23	10.2
Grandfather	7	3.1
Grandmother	7	3.1
Other	17	7.5

Table 3. Instrument for IBD self-care agency survey results

	All participants (n = 225)	UC (n = 72)	CD (n = 153)	p value	
Ability to acquire knowledge					
You are aware of the complications of IBD	3.03±1.22	2.90±1.18	3.11±1.21	0.191	
You are aware about the relationship between inflammation and eating	3.63±0.99	3.34±1.02	3.77±0.95	0.002*	
You are aware about the relationship between stress and inflammation	3.75±1.10	3.86±1.05	3.70±1.12	0.333	
You are aware that inflammation (CRP) can be high without symptoms	3.00±1.41	2.51±1.41	3.24±1.33	0.000*	
You are aware that colds and other health problems can affect inflammation	3.63±1.23	3.38±1.39	3.74±1.13	0.114	
Ability to cope with stress					
You always feel tense about properly controlling your IBD[a]	2.30±1.33	2.44±1.40	2.24±1.30	0.317	★
You cannot sleep at night when you think about IBD[a]	0.88±1.06	0.93±1.05	0.86±1.07	0.587	※
You can deal with stress when it arises	2.85±1.08	2.66±1.12	2.95±1.05	0.050	★
You are often in a depressed mood[a]	2.22±1.33	2.38±1.21	2.14±1.38	0.179	★
You are stressed about the support you are getting from others[a]	1.10±1.15	1.12±1.17	1.09±1.15	0.886	※
Ability to make the most of the support available					
You have someone to encourage you to continue your self-management	3.00±1.41	3.02±1.46	3.01±1.37	0.892	
You have someone you can talk to about your questions, concerns, and worries when you want (or need) advice	3.37±1.26	3.31±1.27	3.41±1.23	0.644	
You have someone who can do for you what you cannot do for yourself, which is necessary to keep you healthy	2.95±1.48	2.83±1.48	3.03±1.47	0.334	
You have someone who is the first to notice when your body is not feeling well (e.g., diarrhea, abdominal pain)	2.71±1.52	2.63±1.48	2.77±1.53	0.543	
You are getting the support you want	3.53±1.13	3.47±1.16	3.58±1.10	0.488	
Monitoring ability					
You are realizing the benefits of self-management	3.26±1.09	3.40±0.91	3.20±1.17	0.233	★
You judge your physical condition, diet, and exercise by checking your symptoms	3.77±0.86	3.68±0.91	3.83±0.83	0.236	★
Recall later what you have determined from your physical condition, diet, and activities and consider whether it is correct	3.40±1.18	3.43±1.14	3.38±1.21	0.847	
You can predict if the CRP levels (a measure of inflammation) in your blood draw are going to be high	2.46±1.46	2.01±1.44	2.67±1.43	0.001*	
You can predict whether you develop symptoms of inflammation (diarrhea, fever, bloody stool, etc.)	2.78±1.27	2.59±1.34	2.87±1.23	0.132	

Table 3 (continued)

	All participants (n = 225)	UC (n = 72)	CD (n = 153)	p value	
Application or adjustment ability					
You understand the extent and progression of your disease	3.95±0.79	4.04±0.73	3.91±0.82	0.367	★
You can envision your life (how you spend your day, your activities, etc.) in concrete terms	3.39±1.09	3.37±1.16	3.40±1.06	0.918	★
Try to devise self-management to fit your lifestyle	3.31±1.04	3.44±1.08	3.26±1.03	0.184	
You can adjust your self-management to changing life circumstances (e.g., when you are busy, at special events, when you have urgent business, when you are entertaining, etc.)	3.01±1.17	3.11±1.16	2.98±1.18	0.477	★
You always try to look at your condition (body, mind, and life) in a calm way	3.25±1.05	3.40±0.97	3.20±1.07	0.230	★
Motivation to self-manage					
You are interested in IBD	4.04±1.05	4.22±0.80	3.96±1.14	0.243	※
You have every reason to want to do self-management	3.78±1.09	3.88±0.98	3.73±1.14	0.437	★
Self-management is the key to achieving the life you want	3.79±0.95	3.86±0.93	3.77±1.14	0.570	
You talk to your health care provider about your self-management and living situation	3.52±1.04	3.44±1.08	3.57±1.00	0.407	
You want to manage yourself better while getting the support you need	3.51±1.37	3.68±1.25	3.44±1.41	0.303	
Ability to self-manage					
You have a relaxed approach to self-management	3.58±0.97	3.48±1.10	3.62±0.91	0.423	
You think you could do with some self-management	3.62±0.90	3.52±0.88	3.67±0.90	0.149	
Your experience has given you confidence in your self-management	3.20±1.02	3.05±1.03	3.28±1.01	0.146	
You find enjoyment and pleasure in self-management	2.35±1.32	2.36±1.27	2.37±1.35	0.891	★
You find enjoyment and purpose in life and living	3.40±1.16	3.37±1.01	3.42±1.23	0.539	★
Body self-awareness					
You feel the importance and risks of IBD acutely	3.51±1.26	3.47±1.23	3.54±1.28	0.581	★
You have things you take care of to keep yourself in good shape	3.53±1.04	3.63±1.06	3.50±1.02	0.326	★
You always ask your body what it needs	2.52±1.23	2.65±1.20	2.47±1.25	0.311	
You are aware of what the symptoms that arise in you mean	2.95±1.14	2.93±1.12	2.96±1.16	0.638	
You think self-management is self-indispensable	3.65±1.06	3.68±1.01	3.66±1.06	0.945	

Inflammation is indicated by a biomarker to assess the state of the bowel. Mean ± standard deviation in cells. UC, ulcerative colitis; CD, Crohn's disease; IBD, inflammatory bowel disease; CRP, C-reactive protein. ᵃReversal entry marked. ※: items excluded due to ceiling/floor effects. ★: items excluded by factor analysis. Wilcoxon rank sum test for comparison of UC and CD, with * for $p < 0.05$.

Cronbach's alpha was calculated for the entire scale and each subscale to verify internal consistency. Data were analyzed using JMP® version 14.0.0, and $p < 0.05$ was considered statistically significant.

Results

Patients

Of the 250 participants included, 247 (98.8%) responded. Among them, 226 had no deficiencies in the 40 items of self-care ability and were included in the analysis. They had a mean age of 38.8 ± 10.7 (18–75) years, and 149 (65.9%) were men. Furthermore, 153 (67.7%) had CD and 72 (31.9%) had UC. The duration of the disease was 13.4 ± 8.1 (1–43) years. The most common current treatment was biologics (178 [78.8%]), followed by immunomodulators (42 [18.6%]) and 5-aminosalicylic acid agents (35 [15.5%]). The frequency of hospital visits was once every 2 months for 145 patients (64.2%) and once a month for 64 patients (28.3%), with 90% patients visiting the hospital once every 1–2 months (Table 2).

Exploratory Factor Analysis

Of the 40 items, the floor/ceiling effects of "you cannot sleep at night when you think about IBD," "you are stressed about the support you are getting from others,"

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Table 4. Factor analysis of pattern matrix with maximum likelihood Promax rotation (*n* = 225)

Factor name/item	Factor loading					
Entire scale α = 0.904	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Commonality
I Ability to build a human support system, α = 0.861						
You have someone who is the first to notice when your body is not feeling well (e.g., diarrhea, abdominal pain)	0.874	−0.094	−0.067	−0.047	0.151	0.743
You have someone who can do for you what you cannot do for yourself, which is necessary to keep you healthy	0.825	0.018	−0.117	0.061	−0.066	0.633
You have someone you can talk to about your questions, concerns, and worries when you want (or need) advice	0.669	0.084	0.143	0.009	−0.073	0.562
You have someone to encourage you to continue your self-management	0.668	−0.054	0.199	−0.013	−0.072	0.520
You are getting the support you want	0.504	0.047	0.044	0.216	0.130	0.537
II Ability to acquire knowledge, α = 0.765						
You are aware of the relationship between inflammation and eating	−0.015	0.678	0.128	0.107	−0.152	0.508
You are aware of the relationship between stress and inflammation	−0.164	0.636	0.005	0.195	−0.022	0.437
You are aware that colds and other health problems can affect inflammation	0.112	0.604	0.142	−0.109	−0.042	0.439
You are aware of the complications of IBD	0.002	0.585	0.035	−0.023	0.076	0.395
You are aware that inflammation (CRP) can be high without symptoms	0.007	0.501	−0.160	0.047	0.202	0.336
III Ability to maintain self-manage, α = 0.820						
You think self-management is self-indispensable	0.031	0.016	0.676	0.020	0.057	0.536
You want to manage yourself better while getting the support you need	0.049	−0.014	0.654	−0.027	−0.039	0.412
Self-management is the key to achieving the life you want	0.018	0.032	0.591	0.094	0.021	0.458
Try to devise self-management to fit your lifestyle	−0.053	−0.057	0.510	0.132	0.387	0.618
Recall later what you have determined from your physical condition, diet, and activities and consider whether it is correct	−0.076	0.019	0.490	−0.146	0.395	0.422
You talk to your health care provider about your self-management and living situation	0.105	0.135	0.457	0.083	0.094	0.457
IV Ability to self-manage, α = 0.847						
Self-management is the key to achieving the life you want	0.061	0.025	0.052	0.818	0.020	0.796
Your experience has given you confidence in your self-management	−0.012	0.000	−0.073	0.817	0.213	0.767
You have a relaxed approach to self-management	0.058	0.059	0.096	0.647	−0.117	0.501
V Ability to self-assess, α = 0.796						
You always ask what your body needs	−0.038	−0.155	0.134	0.184	0.685	0.603
You are aware of what your symptoms that arise mean	0.014	0.031	0.134	0.085	0.615	0.551
You can predict whether you will have symptoms of inflammation (diarrhea, fever, bloody stool, etc.)	0.029	0.471	−0.043	−0.109	0.546	0.656
You can predict if the CRP levels (a measure of inflammation) in your blood draw are going to be high	0.079	0.394	−0.110	−0.095	0.543	0.561
Factor contribution	4.436	3.990	4.761	4.432	4.273	
Factor contribution ratio	19.28	17.35	20.70	19.27	18.57	
Cumulative contribution rate	19.28	36.63	57.34	76.61	95.19	

IBD, inflammatory bowel disease; CRP, C-reactive protein.

and "you are interested in IBD" were identified and excluded in the subsequent analyses. The inter-item correlation analysis showed that no item had a correlation coefficient of ≥0.8. Some items with correlation coefficients of ≥0.7 were not excluded because there were no similar items (Table 3).

Factor analysis with maximum likelihood Promax rotation was conducted on 37 items. Based on the screen plot results, the factor analysis was repeated after excluding items with commonality >0.1 or 1.0, or with factor loadings >0.40. The following items were excluded from the factor analysis: "you always feel tense about properly controlling your IBD"; "you can deal with stress when it arises"; "you are often in a depressed mood"; "you are realizing the benefits of self-management"; "you judge your physical condition, diet, and exercise by checking your symptoms"; "you understand the extent and progression of your disease"; "you can envision your life (how you spend your day, your activities, etc.) in concrete terms"; "you can adjust your self-management to changing life circumstances (e.g., when you are busy, at special events, when you have urgent business, when you are entertaining, etc.)"; "you always try to look at your condition (body, mind, and life) in a calm way"; "you have every reason to want to do self-management"; "you find enjoyment and pleasure in self-management"; "you find enjoyment and purpose in life and living"; "you feel the importance and risks of IBD acutely"; and "you have things you take care of to keep yourself in good shape." Thereafter, 14 items were excluded, and 23 items with 5 factors were used. The cumulative contribution ratio was 95.19% (Table 4).

Factor 1 included five items, which were in agreement with the IDSCA's ability to make the most of the support available. However, considering the IBD characteristics, we cannot confirm that social resources are in place and being used because of the lack of social recognition of IBD. Therefore, we interpreted it as the ability to build a human environment that provides support to patients from their surroundings according to their illness. We named it ability to build a human support system.

Factor 2 included five items, which matched with the items of the ability to acquire knowledge in the IDSCA. We named it ability to acquire knowledge.

Factor 3 included six items. These items indicate that the patients should continuously evaluate and modify their daily self-care with the support of medical caregivers and others and aim to live the life they desire. Therefore, we named this factor as the ability to maintain self-manage, interpreting it as the power to continuously self-manage to live the life the patients desire.

Factor 4 included three items included in the ability to self-manage in the IDSCA. This factor was interpreted as the ability to show mental composure and self-confidence for self-management, and was named same as its name in the IDSCA.

Factor 5 included four items. We named this factor as the ability to self-assess, which was interpreted as the ability to assess the patient's condition according to subjective symptoms and laboratory data values and to apply the results to future life.

Cronbach's alpha coefficient was 0.904 for the 23 items and 0.765–0.861 for each factor.

Discussion

The data collection rate was high (98.8%), with 153 and 72 patients with CD and UC, respectively. The use of infusion or injection biologics was common in Clinic A and commonly used in patients with CD. Most patients who responded during infusion or between injections could submit the survey on the day of distribution as they had enough time, which facilitated their active participation and led to a high response rate.

Factors that encompass self-care ability of patients with IBD were as follows: ability to build a human support system, ability to acquire knowledge, ability to maintain self-care, ability to self-manage, and ability to self-assess with five, five, six, three, and four items, respectively. The existing tools for measuring self-care abilities aim to present self-care abilities at a single behavioral level, such as sleep and exercise [17]. However, in this study, self-care abilities were defined by combining various self-management activities rather than considering them as single behavioral units.

The ability to build a human support system is the ability to find people around them who understand the disease and can provide support or ask for support when needed and to prepare the human environment for living. Patients with IBD need to cope with life events and adjust their lives with the help of their physicians, nurses, surrounding family members, and colleagues and supervisors in the workplace. Purc-Stephenson et al. [27] reported that "social isolation" is a harmful effect of IBD, and avoiding this effect requires the understanding and support of the surrounding community. Nasu et al. [28] reported that employed patients with IBD may not disclose their disease in the work environment because they "do not want to cause trouble or worry." When the condition worsens, patients forcibly work because they "do not want people to think that they are not capable of

self-management" [28]. Dibley et al. [29] reported that people closely related to patient's family may not provide the expected support and stigmatize the patient. Furthermore, Yamamoto et al. [30] reported that patients may encounter problems such as stool leakage and other physical condition that they cannot disclose to their family. Therefore, the physical manifestation of IBD is not easily recognized, and the characteristics of having defecation problems make the establishment of a support system in social life difficult. Patients with IBD must build a support system by informing their trusted people and understand the disease before using support services.

The ability to acquire knowledge means the ability to understand and acquire knowledge about IBD and information that is fundamental to self-care. Lesnovska et al. [31] reported that the knowledge needs of patients with IBD change with the disease course, especially during diagnosis and relapse, and that identifying these knowledge needs in consideration of their disease history and medical condition is important to facilitate their knowledge acquisition. Some patients use immune-related drugs such as biologic agents, and the knowledge required for vaccination and precautions against infectious diseases may differ depending on the used drug. Tools have been developed to measure patients' knowledge of IBD according to their condition and treatment [32]. The ability to acquire knowledge refers to the ability to incorporate the necessary knowledge into the patients' life to achieve a better state of well-being, health, and peace of mind, considering the disease history and condition.

The ability to maintain self-care is the ability to continuously evaluate and modify daily self-care practices and indicate what they seek in their desired way of life. Many patients with IBD develop the disease during adolescence and adulthood and live with IBD for long. Therefore, supporting patients' ability to continue self-management is crucial in maintaining their independent self-care. Additionally, they are forced to restructure various aspects of their lives, such as employment and home life [33, 34], and are expected to reconsider their self-care practices. Therefore, health care professionals should review the existing self-management depending on the circumstances. Yabushita reported that while patients with IBD feel "normal" as they continue to manage their disease, they expand their lives to maintain the perceived "normal" state [35]. The "normal" for healthy people is difficult for patients with IBD; these patients can only achieve a "normal" life after considerable efforts and time to overcome such difficulties. Continuous self-management without strain is crucial to maintain a normal state and an indispensable ability to achieve self-actualization for the future through repeated evaluation

and correction of the patients' daily physical and mental conditions.

The ability to self-manage refers to the ability to evaluate one's own personality in light of illness. This factor focused mainly on mental aspects, such as self-confidence in self-management and mental comfort. Successful experiences through self-care may impart self-confidence in self-management and a relaxed mind [35, 36]. However, IBD-related restrictions on the lives of patients resulting from treatment and recuperation make them socially isolated and susceptible to identity loss [37, 38]. Therefore, self-care in the context of illness should be not driven by IBD. As IBD requires lifelong medical care, whether patients with IBD can live with the disease for the rest of their lives remains uncertain [39]. Self-management, such as strict dietary restrictions, can hinder them from living their own lives and can be a source of increased uncertainty. Therefore, the self-confidence and comfort cultivated through successful experiences will lead to self-management that is unique to the patient. This event can provide a positive view of self-management in continuing lifelong medical treatment, foster patient-oriented self-care, and help patients cope with the uncertainties caused by IBD.

Finally, the ability to self-assess is the ability to evaluate patients' own condition according to their symptoms and laboratory data and apply this evaluation to their own lives. Patients' own senses are important in detecting IBD progression; however, as IBD symptoms are diverse and individualized, patients recognize disease exacerbation later [40]. Measuring their ability to assess their body with their own senses and applying the assessment to their daily lives can help them understand their own disease state. Trivedi et al. [41] reported that patients with IBD considered various symptoms. Few patients considered intestinal mucosa or histological inflammation as a relapse. The course of IBD is comprehensively evaluated based on symptoms, biomarker levels, and endoscopic and imaging examination results. However, these factors can only be ascertained at a medical institution; in particular, endoscopic examinations are not frequently performed because they are invasive and can affect patients' social life. Additionally, same symptoms may medically indicate a relapse based on biomarker levels and intestinal mucosa status assessed. Therefore, the self-assessment ability of patients with IBD refers to the ability to self-determine whether their current symptoms are relapsing symptoms that require medical attention or they are lifestyle-related symptoms that can be managed by them. It is essentially the ability to immediately appropriately respond to changes in disease status to improve patients' daily life.

A distinct feature of the survey was that it compared self-care abilities between patients with UC and those

with CD. The significantly higher scores for self-care abilities related to diet and inflammation in patients with CD compared with those with UC may reflect the disease characteristics of CD. Accordingly, the need for situational diet and nutritional therapy and the dynamic nature of C-reactive protein (CRP) levels in patients with CD may be associated with their self-care characteristics, leading to a significant difference in self-care abilities between patients with CD and those with UC. Therefore, the influence of pathological differences in self-care items related to nutrition and inflammation should be considered when interpreting our results. Despite the increasing incidence of IBD, Japan has a limited number of nurses specialized in IBD. The five factors of self-care ability identified in this study are useful for nurses to understand patients with IBD. These factors provide a common perspective for nurses in supporting self-care for these patients. We believe that a comprehensive assessment of patients' self-care ability will help identify issues and provide clues for self-care support. The relationship with nurses allows patients to reflect objectively on their self-care abilities and give meaning to their own self-care activities. They can also think about what kind of self-care is necessary in their daily lives, and can connect it to their actions in their daily lives. In addition, because CRP, which was used in each factor, is a biomarker of inflammation in IBD, it is important to focus on the patients' responses to other biomarkers, such as fecal calprotectin. Therefore, CRP levels should be considered an indicator of intestinal inflammation when using the current self-care ability measurement tool.

Clinic A specializes in IBD and has a follow-up system to counsel and provide lifestyle guidance to patients by specialists. Therefore, patients attending Clinic A possibly have a high level of self-care ability. However, this is a cross-sectional study conducted at one institution, and approximately 80% of patients had moderate or higher disease levels even with the use of biologics. In addition, the impact of IBD on self-care abilities was not examined. However, considering that the target population has a medical condition that permits outpatient visits, the results should be considered representative of the self-care abilities of patients with IBD within a certain disease activity range. Thus, the results may not be generalizable.

Conclusion

Factors in the IDSCA designed for patients with diabetes that reflect the self-care ability of patients with IBD were extracted. The self-care agency comprised 23 items with five factors. The evaluation of these factors in patients with IBD can help nurses understand their patients and provide an opportunity to patients to reflect on their self-care practices and understand their own self-care ability.

Statement of Ethics

The purpose of the study was explained, and permission was obtained from the IDSCA developer. The survey was conducted anonymously. The purpose and method of the study, participation of free will, no disadvantages for refusal, and plans for presentation at academic conferences and submission to academic papers were explained in writing, and written informed consent was obtained for participation, and consent for participation was considered upon submission of the survey form. The data obtained were used for research purposes and handled anonymously. This study protocol was reviewed and approved by the medical ethics review committee of the institution to which the researcher belongs, approval number (2019013).

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Author Contributions

M.K., N.S., Y.F., and C.M. initiated the study from conception to data analysis; H.M. and K.S. collected data, reanalyzed the data, and summarized the study results.

Data Availability Statement

The data that support the findings of this study are not publicly available due to, e.g., privacy reasons but are available from the corresponding author (H.M.) upon reasonable request.

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