# **ORIGINAL PAPER**

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# Development and validation of the chronic obstructive pulmonary disease self-care assessment scale: a concise and comprehensive instrument to assess self-management, decision-making, and coping

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# ABSTRACT

The purpose of this study was to develop and test the reliability and validity of a brief and comprehensive instrument to assess self-management, decision-making, and coping by chronic obstructive pulmonary disease (COPD) patients. A web-based questionnaire was administered to 300 COPD patients and a retest was administered to 100 COPD patients. Cronbach's alpha was used to assess internal consistency, and an intraclass correlation coefficient was calculated to test the reliability of the retest. The convergent and discriminant validities were also examined. Valid responses were obtained from 279 participants in the first survey and 70 participants in the retest. From our analysis, a COPD self-care assessment scale (CSCS) was developed, consisting of seven subscales and 14 items. Cronbach's alpha for the total CSCS score, intraclass correlation coefficient, and scale success rate were 0.80, 0.79, and 100%, respectively. A multivariate analysis showed that CSCS was associated with current smoking (standardized partial regression coefficient [std  $\beta$ ] = -0.30; p < 0.001), long-term oxygen therapy (std  $\beta$  = 0.23; p < 0.001), and social support (std  $\beta$  = 0.24; p < 0.001), but not psychological symptoms or quality of life. The CSCS is also useful in assessing self-management, decision-making, and coping in Japanese COPD patients, and the scale has high reliability and validity.

Keywords: COPD, internet-based survey, self-care assessment scale

Abbreviations: COPD: chronic obstructive pulmonary disease CSCS: COPD self-care assessment scale

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## INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is caused by prolonged inhalation of tobacco

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smoke and other toxic substances. The number of COPD cases is increasing globally, and COPD was the world's third leading cause of death in 2019, according to the 2020 World Health Organization (WHO).<sup>1</sup> COPD affects almost 8.6% of the Japanese population aged  $\geq$  40 years, ie, 5.3 million patients.<sup>2</sup> COPD patients experience worsening respiratory symptoms and deterioration of quality of life (QOL). Productive cough affects 30% of patients.<sup>3</sup> Dyspnea on exertion worsens the symptoms and health-related QOL (HRQOL) by impairing the respiratory function, resulting in decreased physical activity, muscle dysfunction, deconditioning, and dyspnea.<sup>4</sup> The main treatments for COPD are pharmacological and non-pharmacological, mainly including smoking cessation, bronchodilators, infection prevention, respiratory rehabilitation, and self-management education; the non-pharmacological therapies are a core part of the comprehensive respiratory rehabilitation. In a previous study, self-care intervention for COPD patients was associated with fewer hospitalizations and emergency room visits, improved HRQOL,<sup>5-6</sup> and reduced dyspnea,<sup>6</sup> indicating the significance of self-care for COPD patients.

Despite the importance of self-care and QOL in COPD patients, no scale has been developed to measure these. In 2013, the first self-management scale for COPD patients was developed.<sup>7</sup> However, some of the daily life management items did not fit the self-care recommendations in Japan, making it difficult to use the developed self-management scale in Japan. Therefore, a new self-care measurement scale was needed that is consistent with the international report from Global Initiative for Chronic Obstructive Lung Disease (GOLD) to assess the comprehensive aspects of self-care in COPD patients, such as self-management, decision-making, and coping with COPD.

In addition, screening for the need for intervention is necessary to support the self-care of COPD patients. For this purpose, it is useful to identify factors related to self-care. A systematic review<sup>8</sup> reported patient background, socioeconomic status, and health literacy as factors associated with self-care. Furthermore, no study has examined factors associated with comprehensive self-care, consistent with GOLD. The purpose of this study was to test the reliability and validity of a brief and comprehensive instrument to assess self-management, decision-making, and coping in COPD patients.

### **METHODS**

### Participants and procedure

COPD patients with a high need for self-care were assumed to be receiving COPD treatment. Eligibility criteria for the subjects were adults enrolled in a survey panel of a web research company (Rakuten Insight Inc) who had COPD and were receiving COPD-related pharma-cotherapy. Medications included COPD medications (bronchodilators, short-acting muscarinic antagonists [SAMA], long-acting muscarinic antagonists [LAMA] and inhaled corticosteroids [ICS]). Exclusion criteria were presence of dementia and patients aged 39 years or younger. To check the reliability of the resurvey, respondents who had not changed their lifestyle or COPD self-management between the first and second surveys were resurveyed. Participants read the survey instructions and agreed to participate; photos of 53 COPD medications were presented so that they could accurately identify their treatment; the first survey was conducted on 24–27 December 2020 with 300 participants. A second survey was then conducted two weeks later on 8–9 January 2021 with 100 participants to confirm the reliability of the second survey. The study was approved by the Nagoya University Ethics Review Committee.

#### Survey items

COPD self-care assessment scale. As a measure of self-care in patients with COPD, the COPD Patient Self-Management Scale was developed in 2013.7 It had 51 items with four management sub-concepts (Symptom, Daily life, Emotion and Information) and five subconcepts (Self-efficacy). However, it was difficult to use in Japan due to differences in cultural backgrounds and inconsistencies with national practice guidelines. In addition, a simpler scale would be ideal for patients with shortness of breath as a main symptom to answer. Therefore, a review of previous studies was first conducted, and specific sub-concepts to assess patient self-care were identified as topics that GOLD has identified as appropriate for patient education programmes,<sup>3</sup> smoking cessation, basic information on COPD, general approaches to treatment and specific treatment modalities (respiratory drugs and inhalers respiratory drugs and inhaler devices), strategies to minimise dyspnoea, advice on when to seek help, and decision-making during exacerbations. Furthermore, these items were found to be consistent with the national COPD self-care manual, and the scale sub-concepts were set as 'inhaler medication management', 'medical health management', 'symptom management', 'smoke control', 'infection prevention', 'decision-making' and 'psychological management'. The response options were based on the five-stage response method of the previous study.<sup>7</sup>

The subordinate items were asked on a 5-point Likert scale (5 = always, 4 = often, 3 = sometimes, 2 = rarely, and 1 = never). For inhalant medication management, "N/A" was provided as an option when there medications had not been prescribed. A physician and a nurse specializing in respiratory medicine confirmed the content validity, whereas two non-medical individuals confirmed the face validity. The survey was conducted in Japanese, but the items in the Japanese version were translated into English by a native English speaker and back-translated into Japanese by a native English speaker to ensure that the meaning was preserved.

**Bristol COPD Knowledge Questionnaire.** Bristol COPD Knowledge Questionnaire (BCKQ),<sup>9</sup> a scale measuring the knowledge of COPD patients, was translated into Japanese with the consent of the developer since there is no Japanese version of the scale. BCKQ consists of 13 subscales with 65 items. The content and surface validity of the Japanese version were checked using the same method as for the self-care assessment scale.

**Mishel's Illness Uncertainty Rating Scale Japanese Version.** The Mishel's Illness Uncertainty Rating Scale (MUIS-C) Japanese Version<sup>10</sup> measures the disease-related uncertainty of patients with chronic diseases and their families. This scale includes 23 questions, and the total score range is 23–115, with higher scores indicating a higher perception of uncertainty.

**COPD assessment test.** COPD assessment test (CAT)<sup>11,12</sup> evaluates the current COPD status and its effects on health and daily life; it can be used to assess the HRQOL and consists of 8 items. It is scored on a 40-point scale, with higher scores indicating more severe symptoms.

The Four-Item Patient Health Questionnaire for Anxiety and Depression. The Four-Item Patient Health Questionnaire for Anxiety and Depression (PHQ-4)<sup>13</sup> evaluates the psychological distress using two subscales (ie, anxiety and depression) and categorizes the distress as normal (0–2), mild (3–5), moderate (6–8), and severe (9–12). A score  $\geq$  3 indicates psychological distress.

**Short-form 8 Health Survey.** The Short-form 8 Health Survey (SF-8)<sup>14</sup> is an eight-item score assessment of health status. Higher scores indicate better QOL. The scoring method is scored for each of the eight items and two summary scores. Physical Component Summary (PCS) and

Mental Component Summary (MCS) can be calculated, indicating physical and mental health.

#### Subject background

The subject background included age, gender, BMI, current smoking, use of long term oxygen therapy (LTOT), residential status, highest education, work, social support, details of medication, comorbidities, description of COPD from healthcare providers, and description of infection prevention from healthcare providers.

## Retest items

The retest questionnaires included COPD self-care assessment scale (CSCS), BCKQ, and changes in the lifestyle and self-management of COPD between the two surveys. We evaluated the change status on a 4-point Likert scale from "very much changed" to "not changed at all" due to coronavirus infection outbreak during the survey period.

#### Analysis

SPSS ver 25.0 for Windows was used for statistical analysis. A two-tailed test was conducted at a significance level of 5%.

#### Development and validation of CSCS

We analyzed each item and assessed the ceiling and floor effects by calculating the mean  $\pm$  standard deviation of values outside the upper and lower limits. Next, we conducted exploratory factor analysis with promax rotation to assess factor validity. We selected two items for each factor as the final CSCS with an emphasis on content validity. During this process, some selected items had ceiling effects or factor loadings of < 0.3. To determine the reliability, we calculated the Cronbach's alpha for internal consistency and intraclass correlation coefficient (ICC) and agreements between two surveys for test-retest reliability.

The ICC was interpreted as poor (ICC < 0.5), moderate (0.5  $\leq$  ICC < 0.75), good (0.75  $\leq$  ICC < 0.9), and excellent (0.9  $\leq$  ICC).<sup>15</sup> We evaluated the convergent and discriminant validities using multitrait scaling analysis.

#### Factors associated with CSCS

We performed exploratory analysis of the associations between CSCS and potential factors, such as knowledge, uncertainty, and background. We used t-test, analysis of variance, and Pearson's product rate correlation coefficient for univariate analysis. Then, we performed regression analysis with backward selection for multivariate analysis. We selected potential factors with p < 0.05 in the univariate analysis after considering multicollinearity based on Variance Inflation Factor (VIF)  $\geq 10$ .

#### RESULTS

#### Response status

Consent to respond to the survey was obtained from 300 patients, but a total of 279 valid responses were obtained (valid response rate: 93%), excluding a total of 21 patients who were not receiving medication (n=14) or were in their 20s (n=1), were in their 30s but not receiving medication (n=2), were in their 20s and had a history of Alzheimer's disease (n=1), or were in their 30s and had a history of Alzheimer's disease (n=3).

The number of responses to the retest was 100 (response rate: 100%), with 70 valid responses

(valid response rate: 70%); all 70 respondents answered that there had been little or no change in lifestyle and self-management compared to the first survey.

### Subject background

Background characteristics showed that 93.2% of patients were male, 41.9% were 65–74 years old, and 40.9% were employed. The highest education level was university for 50.5% (Table 1).

	n	%	Mean ± SD	Univariate anal total CSCS	ysis with scale
				Mean ± SD	р
Age			66.8±9.8		
40–64y	104	37.3		59.1±18.2	0.127
65–74y	117	41.9		61.8±15.4	
≥ 75y	58	20.8		64.4±14.8	
Sex					
Male	260	93.2		60.8±19.4	0.878
BMI			23.2±3.7		
Less than 18.5	26	9.3		64.5±18.2	0.197
18.5–25	177	63.4		62.0±15.9	
Over 25	76	27.2		58.7±16.8	
Current smoking					
Yes	65	23.3		52.8±19.1	< 0.001
Long term oxygen therapy					
Yes	25	9.0		71.3±14.9	< 0.001
Living situation					
Living with family	236	84.6		62.1±16.2	0.058
Living alone	42	15.1		56.8±17.3	
Highest educational level					
Vocational school/Junior college	126	45.2		59.4±15.8	0.058
> College	151	54.1		63.2±16.8	
Work					
Yes	114	40.9		62.4±15.6	0.211
Social support					
Yes	236	84.6		63.1±15.6	< 0.001
Drug therapy for COPD (multiple responses)					
Yes (Prescription of the following drugs:)	279	100			
Breakdown bronchodilator (theophylline)	60	21.1			
Bronchodilator (beta-stimulant)	16	7.0			
SAMA	4	1.4			
LAMA	88	30.9			
LABA+LAMA	85	29.9			

Table 1 Background of COPD patients (n=279)

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LABA+ICS	100	35.1			
ICS+LABA+LAMA	41	14.4			
Comorbid diseases					
Cardiovascular disease				61.2±17.3	0.912
Hypertension	120	43.0			
Myocardial infarction, arrhythmia, angina pectoris	30	10.8			
Metabolic disorders				61.6±18.7	0.875
Dyslipidemia (hyperlipidemia)	57	20.4			
Diabetes or metabolic syndrome	45	16.1			
Respiratory disease				66.8±18.5	0.007
Asthma	53	19.0			
Cerebrovascular disease				69.0±25.6	0.450
Cancer	27	9.7		63.8±14.0	0.420
Mental disorder				65.9±14.6	0.199
Depression or depression state	17	6.1			
Schizophrenia	4	1.4			
Explanation of COPD from health workers (before Covid19 epidemic)					
Yes	225	80.6		62.9±15.7	0.003
Explanation of infection prevention from healthcare workers (during Covid19 epidemic)					
Yes	92	33.0		66.1±15.3	0.001
Uncertainty of illness, r			65.0±11.0	-0.01	0.910
BCKQ Percentage of correct answers, r					
Epidemiology			38.3±22.8	0.01	0.891
Aetiology			54.1±25.9	0.15	0.016
Symptoms			41.0±23.8	0.16	0.008
Breathlessness			28.3±19.1	0.15	0.014
Phlegm			39.6±30.3	0.24	< 0.001
Infections			28.0±24.1	0.18	0.003
Exercise			40.5±25.3	0.25	< 0.001
Smoking			53.7±21.9	0.10	0.098
Vaccination			53.6±26.2	0.18	0.003
Inhaled bronchodilators			17.1±22.2	0.21	< 0.001
Antibiotic			28.8±29.5	0.16	0.007
Oral steroids			15.6±21.7	0.15	0.014
Inhaled steroids		-	10.2±18.4	-0.06	0.314

SD: standard deviation BMI: body mass index COPD: chronic obstructive pulmonary disease SAMA: short-acting muscarinic antagonist LAMA: long-acting muscarinic antagonist LABA: long-acting beta2–agonist ICS: inhaled corticosteroid BCKQ: bristol COPD knowledge questionnaire r: Pearson's product-moment correlation coefficient CSCS: COPD self-care assessment scale

## Reliability and validity of CSCS

The results of the COPD self-care assessment scale (Table 2). Ceiling effects were found in health management for medicine, inhalant medication management, and oral care for infection prevention, whereas no floor effects were found. Of these items, the percentage of respondents who answered "always" did not exceed 75%. Since there were no items with ceiling effect but some items showed extremely skewed responses, we did not delete items to emphasize content validity.

	Always	Often	Some- times	Almost never	Not at all	Not applicable	Invalid answer	Mean ± SD
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	-
Inhalant management								
I gargle after inhalation.	115 (41.2)	31 (11.1)	29 (10.4)	40 (14.3)	30 (10.8)	24 (8.6)	10 (3.6)	3.66±1.49
Taking measures to remember using the inhalant medications to inhale the inhalation medicine prescribed by the doctor so that the patient can inhale as instructed by the doctor.	165 (59.1)	46 (16.5)	29 (10.4)	16 (5.7)	11 (3.9)	4 (1.4)	8 (2.9)	4.27±1.13
Health management for medicine								
No smoking.	207 (74.2)	12 (4.3)	9 (3.2)	14 (5.0)	37 (13.3)	-	-	4.21±1.46
Get the flu vaccine every year.	155 (55.6)	31 (11.1)	28 (10.0)	20 (7.2)	45 (16.1)	-	-	3.83±1.54
Symptom management								
I am trying to avoid movements that aggravate shortness of breath.	26 (9.3)	40 (14.3)	63 (22.6)	80 (28.7)	70 (25.1)	-	-	2.54±1.27
Checking symptoms and physical condition related to COPD every day.	73 (26.2)	77 (27.6)	64 (22.9)	39 (14.0)	26 (9.3)	-	-	3.47±1.27
Smoke measures								
I am trying to avoid inhaling dust, smoke, and harmful fumes.	58 (20.8)	86 (30.8)	62 (22.2)	45 (16.1)	28 (10.0)	-	-	3.36±1.26
I take measures against passive smoking.	51 (18.3)	57 (20.4)	50 (17.9)	68 (24.4)	53 (19.0)	-	-	2.94±1.39
Infection prevention								
Keeps oral cavity clean (brushes teeth and cleans dentures if present).	128 (45.9)	97 (34.8)	42 (15.1)	9 (3.2)	3 (1.1)	-	-	4.21±0.89
Hands are always washed when returning home, after toileting, and before meals.	121 (43.4)	97 (34.8)	42 (15.1)	13 (4.7)	6 (2.2)	-	-	4.13±0.98
Decision making								
I am trying to communicate with medical professionals.	67 (24.0)	72 (25.8)	81 (29.0)	36 (12.9)	23 (8.2)	-	-	3.44±1.22
I am finding places where I can talk to them about my illness.	46 (16.5)	66 (23.7)	63 (22.6)	66 (23.7)	38 (13.6)	-	-	3.06±1.29
Psychological management								
When I feel upset or anxious, I talk to my relatives or friends.	14 (5.0)	49 (17.6)	75 (26.9)	81 (29.0)	60 (21.5)	-	_	2.56±1.16
When I feel depressed, I reflect on the reasons and try to resolve them	13 (47)	54 (19.4)	79 (28-3)	83 (29.7)	50 (17.9)	-	-	2.63±1.12

Table 2 Descriptive statistics of self-care assessment scale for COPD patients (n=279)

The exploratory factor analysis of the COPD self-care assessment scale is presented (Table 3). One of the items in "inhalant management" had a factor loading of 0.23; however, we did not exclude it because it is important for evaluating correct inhalant management. The other items had factor loadings of > 0.3 and commonality of > 0.28.

			Fa	actor loadi	ng			
	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII	Commonality
Factor I: Psychological management (	α=0.81)							
When I feel upset or anxious, I talk to my relatives or friends.	0.845	-0.006	0.024	-0.011	-0.024	-0.031	0.076	0.724
When I feel depressed, I reflect on the reasons and try to resolve them.	0.739	0.063	0.047	0.038	0.068	-0.005	-0.122	0.660
Factor II: Smoke measures (\alpha=0.75)								
I am trying to avoid inhaling dust, smoke, and harmful fumes.	-0.070	0.965	0.047	-0.074	0.094	-0.106	-0.040	0.838
I take measures against passive smoking.	0.173	0.645	-0.095	0.028	-0.064	0.065	0.021	0.506
Factor III: Decision making ( $\alpha$ =0.74)								
I am trying to communicate with medical professionals.	-0.038	0.022	0.854	-0.033	0.035	-0.016	-0.009	0.710
I am finding places where I can talk to them about my illness.	0.224	-0.070	0.633	-0.033	-0.052	0.068	0.048	0.547
Factor IV: Infection prevention ( $\alpha$ =0.5	6)							
Keeps oral cavity clean (brushes teeth and cleans dentures if present).	0.030	-0.129	-0.059	0.825	0.098	-0.065	-0.044	0.544
Hands are always washed when returning home, after toileting, and before meals.	-0.014	0.225	0.011	0.528	-0.180	0.131	0.051	0.502
Factor V: Symptom management (a=0	.55)							
I am trying to avoid movements that aggravate shortness of breath.	0.025	0.023	-0.017	-0.050	0.636	0.134	-0.043	0.456
Checking symptoms and physical condition related to COPD every day.	0.028	0.060	0.055	0.174	0.461	-0.080	0.127	0.454
Factor VI: Inhalant management (a=0.	.44)							
I gargle after inhalation.	-0.008	-0.074	0.008	-0.022	0.080	0.711	-0.058	0.478
Taking measures to remember using the inhalant medications to inhale the inhalation medicine pre- scribed by the doctor so that the patient can inhale as instructed by the doctor.	-0.141	0.110	0.186	0.119	0.049	0.272	0.046	0.278
Factor VII: Health management for me	edicine (o	=0.35)						
No smoking.	0.041	0.008	-0.119	-0.089	0.059	0.077	0.643	0.416
Get the flu vaccine every year.	-0.078	-0.043	0.170	0.060	-0.054	-0.152	0.420	0.182

 Table 3 Results of factor analysis of the COPD self-care assessment scale (CSCS) for COPD patients (n=245)

Initial eigenvalue cumulative%	30.462	41.253	49.310	56.912	63.958	69.990	75.774
Interfactor correlation							
Ι	1.000	0.409	0.493	0.268	0.454	0.254	0.208
П		1.000	0.432	0.553	0.523	0.389	0.502
III			1.000	0.392	0.506	0.375	0.284
IV				1.000	0.366	0.449	0.483
V					1.000	0.378	0.439
VI						1.000	0.343
VII							1.000

Cronbach's alpha = 0.80

The reliability and validity of the COPD self-care assessment scale are presented (Table 4). The mean  $\pm$  standard deviation of the total CSCS score was 61.3  $\pm$  16.4. The Cronbach's alpha for the total CSCS score was 0.80 and the range of Cronbach's alpha for the subscale scores was 0.35–0.81. The resurvey reliability was found to be ICC = 0.79 for the total CSCS score and the range of ICC for the subscale scores was 0.48–0.97. The scaling success rate, which assessed the validity, was 100% for the total and subscale scores. To examine the concurrent assessment validity of the CSCS, a variable-adjustment analysis was conducted on its association with related symptoms, psychological symptoms, quality of life, and self-care. Results showed no association with total CSCS scores, but CAT scores were independently associated with symptom management, with higher scores correlating with self-care (Pearson's product-moment correlation coefficient [r] = 0.30, p = .001). Low levels of anxiety and depression were present but were not associated with other self-care subscales. The physical component summary was significantly correlated with symptom management (r = -0.23, p = .007) and decision making (r = -0.04, p = .036).

#### Factors associated with CSCS

Univariate analysis was performed for self-care and patient background of COPD patients (Table 1), and multivariate analysis of significant variables (Table 5).

The multivariate analysis showed that the total CSCS score was significantly higher for the following variables: current smoking (standardized partial regression coefficient [std  $\beta$ ] = -0.30, p < 0.001), LTOT (std  $\beta$  = 0.23, p < 0.001), social support (std  $\beta$  = 0.24, p < 0.001), and respiratory disease (std  $\beta$  = 0.15, p = 0.007). Significantly higher total CSCS score was noted with higher BCKQ symptoms (std  $\beta$  = 0.14, p = 0.013) and exercise knowledge (std  $\beta$  = 0.21, p < 0.001).

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	Mean ± SD	Cronbach's alpha	ICC	Convergent validity	Discriminatory validity	Scal	ing s rate	Ċ	11	ГНЛ	4 -	PC	S	MC	S
		4						r	d	r	d	r	d	r	d
Total CSCS score	61.3±16.4	0.80	0.79	0.38-0.90	0.03-0.50	70/70	100%	0.14	0.326	0.10	0.387	-0.07	0.356	-0.17	0.244
Inhalant management	75.1±26.4	0.44	0.96	0.80-0.85	0.12-0.45	10/10	100%	-0.02	0.516	-0.02	0.752	0.03	0.603	0.03	0.500
Health management for medicine	75.6±29.2	0.35	0.97	0.69-0.90	0.28–0.51	10/10	100%	0.00	0.545	0.01	0.202	-0.06	0.611	-0.06	0.178
Symptom management	50.4±26.3	0.55	0.49	0.71-0.81	0.22-0.50	10/10	100%	0.30	0.001	0.12	0.419	-0.17	0.007	-0.17	0.279
Smoke measures	54.0±29.6	0.75	0.75	0.67-0.72	0.19-0.50	10/10	100%	0.17	0.110	0.16	0.104	-0.18	0.896	-0.18	0.134
Infection prevention	79.4±19.4	0.56	0.70	0.62-0.66	0.23-0.46	10/10	100%	-0.02	0.625	0.04	0.871	-0.11	0.463	-0.11	0.241
Decision making	56.4±28.0	0.74	0.48	0.44-0.68	0.13-0.38	10/10	100%	0.06	0.070	-0.02	0.858	-0.04	0.036	-0.04	0.382
Psychological management	40.0±26.1	0.81	0.49	0.38-0.63	0.03-0.31	10/10	100%	0.12	0.953	0.19	0.385	-0.21	0.720	-0.21	0.210

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 Table 4
 Reliability and validity of the self-care rating scale for COPD patients (n=245)

Scale items and total CSCS score are rated from 0 to 100 points.

ICC: intraclass correlation coefficient

r: Pearson's product-moment correlation coefficient

CAT: COPD assessment test

PHQ-4: The Four-Item Patient Health Questionnaire for Anxiety and Depression

SF-8: The Short Form-8 Health Survey

PCS: physical component summary MCS: mental component summary

		Table 5         Factor	is associated with C	SCS (multivaria	te analysis) (n=2'	(6/		
	Total CSCS score	Inhalant management	Health management for medicine	Symptom management	Smoke measures	Infection prevention	Decision making	Psychological management
	Std β p	Std β p	Std β p	Std β p	Std $\beta$ p	Std $\beta$ p	Std $\beta$ p	Std β p
Age								
40–64y	I	I	(reference)	I	I	I	I	I
65-74y			0.20 0.001					
≥ 75y			0.21 <0.001					
Sex								
Female	I	I	Ι	I	Ι	(reference)	Ι	I
Male						-0.14 0.021		
Current smoking								
No	(reference)	I	(reference)	(reference)	(reference)	(reference)	I	I
Yes	-0.30 <0.001		-0.43 <0.001	-0.18 0.002	-0.26 <0.001	-0.15 0.014		
Long term oxygen therapy								
No	(reference)	I	Ι	(reference)				
Yes	0.23 <0.001			0.21 <0.001	0.21 0.001			
Living situation								
Not living alone	I	I	(reference)	I	Ι	I	Ι	
Living alone			-0.15 0.003					
Social support								
No	(reference)	I	I	(reference)	I	I	(reference)	(reference)
Yes	0.24 <0.001			0.16 0.006			0.15 0.014	0.19 0.001
Comorbid disease								
Respiratory disease								
No	(reference)	(reference)	I	(reference)	(reference)	I	I	I
Yes	0.15 0.007	0.13 0.047	2	0.16 0.005	0.22 <0.001			

Development of COPD self-care scale

Mental disorder																
No	Ι		I		I		I		I		I		(refere	ence)	I	
Yes													0.12	0.035		
Cerebrovascular disease																
No	Ι		I		(refen	ence)	I		I		I		I		I	
Yes					0.10	0.045										
Explanation of COPD from health workers (before COVID-19 epidemic)																
No	Ι		I		I		I		I		I		(refere	ence)	(refere	ence)
Yes													0.19	0.002	0.12	0.042
Explanation of infection prevention from healthcare workers (during COVID-19 epidemic)																
No	Ι		I		I		I		I		I		(refere	ence)	I	
Yes													0.17	0.003		
Uncertainty of illness	I		I		I		I		I		I		-0.12	0.035	0.23	<0.001
BCKQ																
Actiology	I		I		I		I		I		I		0.13	0.039	I	
Symptoms	0.14	0.013	I		I		0.26	<0.001	I		I		I		I	
Phlegm	I		0.14	0.030	I		I		I		I		0.16	0.013	Ι	
Exercise	0.21	<0.001	I		I		I		0.18	0.002	0.17	0.004	I		0.24	<0.001
Vaccination	I		I		0.19	<0.001	I		I		I		I		I	
Inhaled bronchodilators	I		I		I		I		I		I		I		0.18	0.002
Adjusted R2	0.30		0.04		0.37		0.18		0.18		0.06		0.21		0.22	
Std B: standardized partial regressi	ion coeffic	cient														

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#### DISCUSSION

#### Reliability and validity of CSCS

We developed a scale for assessing COPD self-care, consisting of 14 items in 7 domains: psychological management, smoking control, decision making, infection prevention, symptom management, inhalant medication management, and medical health management. There are several strengths of this scale. First, the scale has good content validity and ability to measure comprehensive concepts in a simple manner. It assesses adherence to treatment as well as decision making and psychological management of COPD patients. Second, the scale had sufficient reliability and validity. In this study, internal consistency and retest reliability were assessed for reliability. In addition, the content, surface, factor, convergent, and discriminant validities were assessed. Third, the survey included few, simple items compared to the content validity. The number of items per subscale was limited to two; however, we emphasized the comprehensiveness of the content, and the scale can only be used with subscales. The scale may be useful for research and clinical purposes.

There are several weaknesses in the self-care assessment of COPD patients. First, there is a ceiling effect. For some items, the mean plus standard deviation exceeded the score range, and some questions had low difficulty level. Although the items were included in the scale because of their content validity, there are limits to their responsiveness. Second, the internal consistency was relatively low. In addition, due to the comprehensiveness of GOLD and Japanese guidelines, diverse items were included, and some items had factor loadings of < 0.3. Third, the range of retest reliability was wide. The ICCs for the subscale scores ranged from moderate to excellent. The two surveys were conducted at a 2-week interval, during the coronavirus pandemic, with the country's first state of emergency being declared in some areas immediately after the retest. Even though valid responses were obtained from participants whose lives had not changed, the conditions were not identical for the two surveys, which may have affected the reliability. This was not a problem with the developed COPD self-care assessment scale; rather, it affected the timing of the survey. The satisfactory ICCs and 100% success rate of the scale are positive indicators of the usefulness of the scale. Fourth, some items in the medical management were marked as "not applicable", which limits inter-patient comparison. Fifth, concurrent validity was lower than the assumption of weak to moderate positive association. The reason may be the cross-sectional study design and confounding due to coronavirus outbreak. The COPD patients needed to improve their self-care due to poor physical and mental health, as well as the infection pandemic. Sixth, the association of CSCS as a comorbidity outcome with psychological symptoms and QOL was minimal and lower than expected; cross-sectional studies have limited ability to demonstrate the relationship between self-care and QOL in COPD patients.

#### Factors associated with CSCS

Total CSCS score was associated with current smoking, LTOT, respiratory disease, and social support. In a previous study, the BCKQ smoking correct response rate was higher than that in the present study, ie, 65.3%<sup>16</sup> and 96%,<sup>17</sup> respectively, suggesting that participants in the present study did not have sufficient knowledge about smoking. Smoking cessation is crucial for COPD treatment. However, smoking may be continued due to a lack of awareness of the adverse effects of smoking due to the health belief model. Interventions may be necessary to promote smoking cessation among smokers.

COPD patients with dyspnea that required LTOT were more likely to practice self-care due to the disease severity; these patients were more familiar with their illness and self-care due to the length of their illness. We believe that COPD patients who have dyspnea that requires LTOT practice self-care out of necessity and are familiar with the disease and self-care due to the prolonged disease duration. An association with respiratory disease (asthma) has also been noted: overlap between COPD and asthma is associated with higher frequencies of exacerbations and severe exacerbations requiring hospitalization compared to COPD patients<sup>18</sup>; these patients may receive focused self-care instructions from their healthcare providers.

Social support was associated with symptom management, decision making, and psychological management. It is necessary to confirm the presence of social support that supports self-care.

Self-care was also related to the symptoms and exercise on the BCKQ, which can be explained by the knowledge-attitude-practice model, in which knowledge is linked to attitude and practice. Knowledge assessment is important for self-care practice. In addition, to encourage self-care, it is necessary to suggest individualized ways to enhance patient empowerment, such as by providing social support.

### Limitations

The limitations of this study are related to bias because this was a web-based survey and many of the participants were young with high internet literacy. In addition, the diagnosis of COPD was self-reported and information on the disease stage and the status of medical treatment could not be obtained; however, efforts were made to enable the participants to make accurate judgments, such as illustrating the drugs used for COPD treatment and evaluating whether the eligibility criteria for the disease have been fulfilled. Based on these results, there are limits to representativeness. The self-care was self-reported and may not reflect the actual state of practice. The survey was performed during the coronavirus disaster. In particular, the survey was conducted again and showed an infection epidemic. This was a time when the public was under pressure to shift to a new lifestyle, and the evaluation was a transitional period in terms of the actual state of self-care among COPD patients. Furthermore, the survey items may not be sufficient as relevant factors for self-care assessment.

## CONCLUSIONS

The CSCS is a 14-item, 7-subscale scale with sufficient reliability and validity for use in research and clinical practice. The CSCS was associated with current smoking status, LTOT, and social support. CSCS was not associated with psychological symptoms or QOL. However, the results may be different inbetween longitudinal studies. In addition, the results of this study do not negate the relationship between self-care and QOL.

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# DISCLOSURE STATEMENTS

*Conflict of interest* None of the authors have any competing interests to declare.

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#### Authors' contributions

Sanae Iwaya contributed to the conception and design of this study, collected data, performed the statistical analysis and drafted the manuscript; Kazuki Sato critically reviewed the manuscript and supervised the whole study process. All authors read and approved the final manuscript.

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