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Validation and verification of the Japanese version of the systemic lupus erythematosus symptom checklist for patient quality of life

Lupus

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Abstract

Objective: The systemic lupus erythematosus (SLE) symptom checklist (SSC) is a patient-reported outcome measure consisting of 38 queries. We translated SSC into Japanese and attempted to validate its usefulness for evaluating the quality of life (QOL) of SLE patients and identify factors that affect QOL.

Methods: Data from the Medical Outcomes Study Short-form 36 questionnaire (SF-36), Japanese LupusPRO, the Japanese version of the SSC (SSC-J) questionnaire, SLEDAI-2k, and the physician global assessment (PGA) were obtained on the same day from 226 SLE outpatients of the Kyoto Lupus cohort at Kyoto University Hospital. Relationships between the total scores or each item of SSC-J and SF-36, Japanese LupusPRO, SLEDAI-2k, or PGA were analyzed by Spearman's rank test.

Results: The total scores of SSC-J correlated with the scores of SF-36 and Japanese LupusPRO. In each item of SSC-J, all 38 items correlated with the physical component summary and mental component summary of SF-36 as well as the Health-Related QOL (HRQOL) scores of Japanese LupusPRO, but not with the non-HRQOL of LupusPRO. SSC-J scores correlated with age, PGA, and corticosteroid doses, but not with SLEDAI-2k.

Conclusions: SSC-J is suitable as a disease-specific QOL assessment tool for SLE.

Keywords

Systemic lupus erythematosus, quality of life, SLE symptom check list, patient-reported outcome

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Introduction

Systemic lupus erythematosus (SLE) is an autoimmune disease that presents with various symptoms, including fever, rash, renal dysfunction, and neurological disorders. Due to treatments with corticosteroids (CS) and immunosuppressants, the mortality and morbidity of this disease have been improved; however, many patients still have disease-related and drug-induced symptoms. A number of disease activity evaluation tools have been developed. The SLE disease activity index (SLEDAI)¹ and British Isles lupus assessment

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group (BILAG)^{2,3} are two major activity indices, and their combination with the physician global assessment (PGA) is currently used as the endpoint for various clinical trials, such as the SLE responder index (SRI)⁴ and BILAG-based composite lupus assessment (BICLA).^{5,6}

The systemic lupus international collaborating clinics (SLICC) damage index (SDI)⁷ is mainly used to evaluate organ damage.

Although clinical remission⁸ is the ultimate treatment goal, it is difficult to attain; therefore, low disease activity has been accepted^{9,10} and organ damage may be prevented.¹¹ However, it currently remains unclear whether patient-reported outcome (PRO) measures or quality of life (QOL) are affected by changes in the treatment goal. Although various SLE-specific PRO tools have recently been reported,^{12–15} LupusPRO is the only one that has been translated into Japanese and validated.¹⁶ Some PRO tools may not be appropriate for patients in different countries due to cultural differences. Therefore, the implementation of an assessment standard of QOL for SLE patients in Japan is urgently needed.

The SLE symptom checklist (SSC)¹⁵ is an SLE disease-specific QOL assessment tool that was established in 2003 by Grootsoorten in the Netherlands and consists of 38 queries for potential disease-related or treatment-related symptoms on a 4-point scale, with a maximum score of 152 points. Although it is still controversial whether SSC is a QOL assessment tool, SSC score was shown to be related to the well-established QOL assessment tool SF-36. Therefore, SSC could be a new SLE-specific QOL assessment tool by assessing the SLE and treatment-related symptoms.

SSC comprises queries of short sentences or simple words that fit in one page, which is useful for assessing QOL repeatedly, such as at every clinic visit.

In the present study, we developed a Japanese version of SSC and verified its usefulness by comparing it to the findings of other QOL evaluation tools, such as MOS 36-Queries Short Form Health Survey^{17–19} (SF-36) and Japanese LupusPRO.¹⁶

Method

Translation and reliability

SSC has 38 symptoms, each of which has five descriptive categories. i.e. Category 1 (0 points): no symptoms; Category 2 (1 point): a symptom exists, but is not burdensome; Category 3 (2 points): a little burdensome; Category 4 (3 points): quite burdensome; and Category 5 (4 points): extremely burdensome. The total score is calculated after tallying the 38 queries (maximum 152 points). A higher score indicates lower patient QOL. The English version of SSC was

translated into Japanese (Supplementary Figure S1) by four Japanese rheumatologists who are proficient in English. The translated SSC was re-translated by a bi-lingual (English and Japanese) native English speaker and was assured for the correct and decent translation by all the translators. We did not change the content of SSC questionnaire because no cultural differences were observed.

Patient

We recruited 250 consecutive SLE patients from the Kyoto Lupus cohort (KLC) who visited Kyoto University Hospital between September 2019 and January 2020. They all met the ACR 1997 diagnostic criteria²⁰ or SLICC 2012 classification criteria.²¹ Questionnaires from 226 patients were returned and analyzed. Patients with complications that severely affected QOL, such as terminal cancer, were excluded.

Ethical considerations

The present study was approved by the Ethics Committee of Kyoto University Hospital as an observational study of SLE using questionnaires. Physicians obtained verbal and written consent from patients before conducting the survey (Approval number R1452-1).

Data collection

Data from self-described symptoms on the SSC-J questionnaire, SF-36, and Japanese LupusPRO on the same day were combined to evaluate QOL. SSC questionnaires that were less than 80% complete were not eliminated and scores were extrapolated based on the average scores of the other items of the patient. A cut-off value of 80% was set based on the distribution of the response rate to the questionnaire (Supplementary Figure S2). SF-36 was scored using the web version scoring program,¹⁹ while LupusPRO was scored as described previously.¹⁶ SLEDAI-2k²² and PGA (physician global assessment) scoring were performed by the attending physicians to assess the disease activity of each SLE patient. PGA scores were obtained by following the SELENA-SLEDAI flare index²³ using a 10-cm scale expressing a 3-point scale. Information on gender, age, disease duration, current treatment, and the presence of other collagen vascular diseases (CVDs) was also collected from electronic medical charts at Kyoto University Hospital.

Statistical analysis

To calculate the internal consistency of items of SSC-J, Cronbach's α coefficient²⁴ was used.

Queries were considered to be reliable when Cronbach's α coefficient was higher than 0.7.

We performed a "test-retest reliability" assessment to examine the reliability of SSC-J. We asked 51 SLE patients who filled out the SSC questionnaire at the visit to fill out the same questionnaire 2 weeks later and send it to us according to the Japanese LupusPRO.¹⁶ We obtained the re-test results from all the patients.

We hypothesized that QOL scores measured by SSC-J would show a significant correlation with those measured by SF-36, which is a general-purpose QOL measurement tool, and by LupusPRO, which is an existing SLE disease-specific QOL measurement tool. We also hypothesized that some of the QOL components measured by SF-36 and LupusPRO are not correlated with SSC-J total scores. We further hypothesized that the QOL of SLE patients concomitant with other collagen vascular diseases (CVDs) might not be evaluated as efficiently as the QOL of SLE patients without other CVDs. The relationships between the total scores of SSC-J and the eight health concepts of SF-36: physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), role limitations due to emotional problems (RE), and mental health (MH); as well as the physical component summary (PCS) and mental component summary (MCS) of SF-36, along with the health-related (HR) QOL (HRQOL) and non-HR QOL (N-HRQOL) of Japanese LupusPRO were analyzed.

Enrolled SLE patients were divided into two groups; only SLE and SLE complicated by other CVDs. In each group, we investigated whether SSC-J functioned as a useful tool for measuring QOL.

We also performed a correlation analysis between each SSC-J component and the PCS and MCS of SF-36 as well as the HRQOL of Japanese LupusPRO. Spearman's rank correlation coefficient was used to verify relationships, and the analysis software R was used.

Results

A total of 250 SLE patients were enrolled. Among these, 21 patients were excluded because of the insufficient completion of SSC-J, Japanese LupusPRO, or SF-36, and 3 were excluded due to the lack of SLEDAI and PGA (physician global assessment). No patients with terminal cancers were included. Therefore, analyses were performed on 226 patients.

As shown in Table 1, the majority of patients were women (92%), the average age was 47.2 years old, and the average disease duration was 17.1 years. Mean SLEDAI-2k and PGA scores were 5.7 and 1.6 points

Table 1. Patient background.

Female, n (%)	210 (93)
Age (y)	47.2 $\pm$ 13.6 ^a
Disease duration (y)	17.1 $\pm$ 10.4 ^a
SLEDAI-2k	5.7 $\pm$ 5.1 ^a
PGA (3-point scale)	1.6 $\pm$ 1.4 ^a
Overlap with other CVDs	22.1%
MCTD	4.4%
SSc	2.2%
PM/DM	1.3%
Vasculitis	0.4%
RA	6.6%
SS	11.5%
Treatment	
CS use (%)	92%
PSL (mg/d)	5.9 $\pm$ 4.0 ^a
IS use (%)	65%
HCQ use (%)	28.3%

PGA: physician global assessment; CVDs: collagen vascular diseases; MCTD: mixed connective tissue disease; SSc: systemic sclerosis; PM/DM: polymyositis/dermatomyositis; RA: rheumatoid arthritis; SS: Sjogren's syndrome; CS: corticosteroid; PSL: prednisolone (equivalent); IS: immunosuppressant; HCQ: hydroxychloroquine.

IS include tacrolimus (33.6%), mycophenolate mofetil (13.7%), azathioprine (12.4%), belimumab (9.7%), cyclosporin A (6.6%), mizoribine (5.8%), methotrexate (4.9%), and rituximab (0.4%). Some patients were taking multiple IS.

^aMean $\pm$ SD.

(3 points maximum), respectively. Most patients (92%) were taking oral CS with an average dose of 5.9 mg/day. Immunosuppressants were used by 65% of patients and hydroxychloroquine by 28%.

Cronbach's α coefficient was 0.94, indicating inter-nal consistency of the items in the SSC-J.

We also performed a test-retest reliability assessment as described in Methods. We obtained 51 test-retest results. The mean interval of test-retest was 16 days (standard deviation: SD was 7.1 days). The mean $\pm$ SD of test and re-test SSC scores were 33 $\pm$ 27.6 and 33 $\pm$ 26.2, respectively, ($p = 1.29 \times 10^{-30}$, $R = 0.967$) indicating the reliability of this tool.

The average total score of SSC-J was 35.7 out of a maximum score of 152. As shown in Supplementary Table S1, fatigue, spontaneous bruises, and ankle edema were the most frequent symptoms (76.4, 66.6, and 66.3%, respectively), whereas fainting (10.6%), fits (12.4%), and genital sores (18.2%) were the least frequent (Supplementary Table S1). The strength of distress was the highest in the items of muscle weakness, vulnerable skin, and fatigue (2.36, 2.27, and 2.24, respectively), whereas it was the lowest in the item of fainting (Supplementary Table S1).

Figure 1 shows the relationships between the total scores of SSC-J and each health scale of SF-36 or with each domain of Japanese LupusPRO. The total score of

SF-36 vs SSC-J				LupusPRO vs SSC-J			
health concept		R	P value	Domain		R	P value
MCS ↑ PCS ↓	PF	-0.44	2.55E-12	HRQOL ↑ N-HRQOL ↓	Lupus symptoms	-0.552	2.18E-19
	RP	-0.47	5.45E-14		Cognition	-0.466	1.45E-13
	BP	-0.53	1.48E-17		Lupus medications	-0.416	6.92E-11
	GH	-0.45	1.78E-12		Procreation	-0.253	0.00012
	VT	-0.53	5.47E-18		Physical health	-0.503	7.10E-16
	SF	-0.5	8.18E-16		Pain / Vitality	-0.657	2.40E-29
	RE	-0.42	4.49E-11		Emotional health	-0.55	3.02E-19
	MH	-0.52	5.09E-17		Body image	-0.491	4.21E-15
	PCS	-0.42	4.43E-11		Desires / Goals	-0.397	5.99E-10
	MCS	-0.54	1.76E-18		Social support	0.328	4.64E-07
			Coping	0.248	0.00016		
			Satisfaction with care	0.079	0.235		
			HRQOL	-0.678	9.14E-32		
			N-HRQOL	0.085	0.201		

Figure 1. Relationships between SSC-J total scores and each health concept of SF-36 or each domain of Japanese LupusPRO. R: correlation coefficient; PF: physical functioning; RP: role limitations due to physical health problems; BP: bodily pain; GH: general health perceptions; VT: vitality; SF: social functioning; RE: role limitations due to emotional problems; MH: mental health; PCS: physical component summary; MCS: mental component summary; HRQOL: health-related quality of life; N-HRQOL: non-HRQOL.

Table 2. Relationships between the total score of SSC-J and SF-36 or LupusPRO in SLE patients with or without other collagen vascular diseases (CVDs).

Health concept or domain	SLE alone (N = 176)		SLE with other CVDs (N = 50)	
	R	p value	R	p value
SF-36 vs. SSC-J				
PF	-0.436	1.50E-09	-0.444	0.00124
RP	-0.449	4.13E-10	-0.508	0.00017
BP	-0.497	2.42E-12	-0.638	6.25E-07
GH	-0.462	1.12E-10	-0.367	0.0087
VT	-0.524	7.98E-14	-0.544	4.49E-05
SF	-0.514	3.04E-13	-0.423	0.0022
RE	-0.462	1.10E-10	-0.239	0.094
MH	-0.554	1.60E-15	-0.378	0.00682
PCS	-0.406	2.32E-08	-0.447	0.00113
MCS	-0.575	6.82E-17	-0.388	0.00539
LupusPRO vs. SSC-J				
HRQOL	-0.677	5.78E-25	-0.672	9.26E-08
N-HRQOL	0.0655	0.387	0.177	0.22

BP: bodily pain; GH: general health perception; MCS: mental component summary; MH: mental health; PCS: physical component summary; PF: physical functioning; RE: role limitations due to emotional problems; RP: role limitations due to physical health problems; SF-36: short-form 36 questionnaire; SLE: systemic lupus erythematosus; SSC-J: the Japanese version of the systemic lupus erythematosus symptom checklist; VT: vitality.

SSC-J correlated with PCS ($p=4.43E-11$, $r=-0.420$) and MCS ($p=1.76E-18$, $R=-0.539$) of SF-36. All eight health concepts correlated with the SSC-J total score. SSC-J scores correlated with the HRQOL of Japanese LupusPRO with $p=9.14E-32$ and $r=-0.678$, whereas no correlation was observed between SSC-J and N-HRQOL.

We hypothesized that the QOL of SLE patients concomitant with other collagen vascular diseases (CVDs) might not be evaluated as efficiently as the QOL of SLE patients without other CVDs. Fifty SLE patients were complicated by other CVDs. As shown in Table 2, negative correlation between SSC-J total score and each health concept of SF-36 or HRQOL of LupusPRO

were mostly significant in SLE patients with other CVDs as shown in SLE patients without other CVDs. These results demonstrated that SSC-J is as effective as SF-36 and Japanese LupusPRO for evaluating QOL regardless of complication of other CVDs.

In assessments of the relationships between each query of SSC-J and the PCS of SF-36, correlations were observed in 33 out of 38 SSC-J queries (Table 3, Supplementary Table S2). The top 3 queries with the strongest correlation were painful muscles, shortness of breath, and painful joints. Queries with no correlation ($p > 0.05$) were itch, skin rash, white fingers in cold weather, fainting, and headache.

Table 3. Top 5 SSC-J items correlating with the PCS and MCS of SF-36 or HRQOL of LupusPRO.

SSC-J item	R	p value
SSC-J vs. PCS of SF-36		
Painful muscles	−0.451	1.24E−12
Shortness of breath	−0.423	3.52E−11
Painful joints	−0.4	5.86E−10
Muscle weakness	−0.391	1.18E−09
Ankle edema	−0.358	3.03E−08
SSC-J vs. MCS of SF-36		
Fatigue	−0.587	3.30E−22
Mood changes	−0.559	7.33E−20
Muscle weakness	−0.407	2.04E−10
Itch	−0.405	2.59E−10
Nightmares	−0.38	4.05E−09
SSC-J vs. HRQOL of LupusPRO		
Fatigue	−0.56	6.06E−20
Muscle weakness	−0.541	1.36E−18
Poor wound healing	−0.51	2.33E−16
Loss of concentration	−0.508	3.97E−16
Mood changes	−0.503	8.45E−16

HRQOL: health-related quality of life; MCS: mental component summary; PCS: physical component summary; SF-36: Short-form 36 questionnaire; SSC-J: the Japanese version of the systemic lupus erythematosus symptom checklist.

Correlations with the MCS of SF-36 were observed in all 38 SSC-J queries. The top 3 queries with the strongest correlation were fatigue, mood changes, and muscle weakness.

We also examined the relationship between each query of SSC-J and the HRQOL of Japanese LupusPRO, which showed correlations with all 38 SSC-J queries. The top 3 queries with the strongest correlation were fatigue, muscle weakness, and poor wound healing.

The effects of disease activity, medication, and age on QOL were analyzed using the PCS and MCS of SF-36, the HRQOL of LupusPRO, and the SSC-J total score. As shown in Table 4, SLEDAI-2k did not correlate with any of the QOL measurement tools, while PGA correlated with the MCS of SF-36, HRQOL of LupusPRO, and SSC-J total score, but not with the PCS of SF-36. CS doses also correlated with the MCS of SF-36, HRQOL of LupusPRO, and the SSC-J total score, but not with the PCS of SF-36. Age correlated with the PCS of SF-36 and SSC-J total score, but not with the MCS of SF-36 or HRQOL of LupusPRO.

We then examined the relationships between each query of SSC-J and age, CS dose, and PGA. Age correlated with 20 queries of SSC-J (Table 5). The top 3 queries with the strongest correlations with age were muscle cramps, disturbed memory, and blue/purple stretch marks on the skin. The top 3 queries having the strongest correlations with CS doses were plump cheeks/face, facial hair growth, and mood changes. The top 3 queries having the strongest correlations with PGA were skin rash, vulnerable skin, and sensitivity to sunlight.

Discussion

In the present study, we developed the Japanese version of SSC and compared it with other QOL measurement tools, namely, SF-36 and Japanese LupusPRO. Similar to the original SSC (English version), SSC-J scores also

Table 4. Relationships between SLEDAI-2k, PGA, corticosteroid dose, or age and the SSC-J total score, PCS and MCS of SF-36, and HRQOL of LupusPRO.

Clinical parameter	SF-36				LupusPRO			
	PCS		MCS		HRQOL		SSC-J	
	R	p value	R	p value	R	p value	R	p value
SLEDAI-2k	0.09	0.179	−0.04	0.547	−0.027	0.689	0.0682	0.307
PGA	−0.118	0.078	−0.158	0.017	−0.212	0.001	0.155	0.0195
CS dose	−0.084	0.208	−0.196	0.003	−0.251	0.0001	0.204	0.002
Age	−0.248	0.0002	0.025	0.704	−0.127	0.056	0.171	0.0099

SLEDAI-2k: SLE disease activity index 2000; PGA: physician global assessment; CS: corticosteroid.

Table 5. Subjective symptoms strongly correlated with age, corticosteroid doses, and PGA.

SSC-J item	R	p value
Age vs. SSC-J		
Muscle cramps	0.416	8.78E-11
Disturbed memory	0.301	4.47E-06
Blue/purple stretch marks on the skin	0.251	1.46E-04
Muscle weakness	0.244	2.16E-04
Blurred vision	0.238	3.25E-04
CS dose vs. SSC-J		
Plump cheeks/face	0.42	4.27E-11
Facial hair growth	0.217	0.00107
Mood changes	0.203	0.00218
Hair loss	0.202	0.00227
Weight gain	0.198	0.00281
PGA vs. SSC-J		
skin rash	0.217	0.00115
Vulnerable skin	0.191	0.00389
Sensitivity to sunlight	0.18	0.00692
Poor wound healing	0.175	0.00842
Chubby cheeks/face	0.168	0.0113
Mood changes	0.168	0.0114

CS: corticosteroids; PGA: physician global assessment; SSC-J: the Japanese version of the systemic lupus erythematosus symptom checklist.

correlated with the scores of all eight health concepts of SF-36.¹⁵ SSC-J scores also correlated with the HRQOL scores of LupusPRO, but not with N-HRQOL scores. These results demonstrate the suitability of SSC-J for accurately measuring the QOL and physical and mental health of patients, but not social QOL.

SSC was originally developed in Dutch and was translated into English and Portuguese.²⁵ SSC-J is the 2nd SSC that was translated into a language other than English. One of the limitations in translation of English version into Japanese is that we did not follow the guidelines for the process of cross-cultural adaptation of PRO measures.²⁶ However, we believe that the translation is accurate and do not need the cultural adaptation. SSC is a lupus-specific PRO tool that has 38 simple queries with a 5-point scale (0–4) in each query and fits in one A4 (or US letter size) page. LupusPRO has 43 queries with a 5-point scale (0–4) and each query has long sentences,¹⁴ LupusQOL has 34 queries of relatively long sentences with a 5-point scale,¹³ and SLEQOL has 40 queries of relatively short sentences with a 7-point scale.¹² Each QOL measure has its own advantages and disadvantages; SSC appears to be useful for assessing QOL repeatedly, such as at every clinic visit, because it fits in one A4 page and does not take long time to fill out. LupusPRO has its short version, Lupus Impact Tracker, and has only 10 queries with a 5-point scale. It may be suitable for measuring changes in QOL, but may not have an adequate number of queries to assess various aspects of QOL.

Another characteristic of SSC is that it asks whether the patient has each symptom or not, whereas other QOL measures mainly ask about the ability to perform physical or social activities, such as restrictions to daily activities, concerns, happiness, and social support. For example, LupusPRO only has four SLE-specific symptoms: hair loss, skin rash, memory loss, and a lack of concentration. Since SSC is the “SLE symptom checklist”, it may evaluate which symptoms are reducing the QOL of each patient. This is a unique property of SSC that differs from other QOL measurement tools.

SSC is a PRO measure that expresses QOL as a total score; it is divided by physical, mental, or social aspects in other PRO measures, including LupusPRO, LupusQOL, SLEQOL, and SF-36. In the present study, SSC-J total scores correlated with all eight subcategories and the physical and mental component summaries of SF-36 as well as with the HRQOL of LupusPRO. These results clearly demonstrated that SSC-J is consistent with other PRO measures and is useful for evaluating the overall QOL of SLE patients. However, SSC-J scores did not correlate with the N-HRQOL of LupusPRO. While SSC-J scores negatively correlated with most of the physical domains of LupusPRO (better the QOL by SSC score, and better the QOL by LupusPRO), SSC-J scores positively correlated with Social support and Coping domains in the N-HRQOL of LupusPRO and negatively correlated with the Desires/Goals domain (Figure 1). Therefore, SSC-J did not correlate with N-HRQOL as a whole. This may be partly attributed to the medical expenses of SLE patients being largely covered by the national health insurance system in Japan and the majority of Japanese not having a specific religion. Therefore, some of the queries of LupusPRO may not be appropriate to the Japanese social, cultural, or habitual background. However, as a basic concept, SSC-J and SF-36 measure health-related QOL,^{17–19} whereas the N-HRQOL of LupusPRO mainly assesses non-health-related QOL.

One of the novel results of the present study is that SSC-J is applicable to SLE patients with other CVDs, including Sjögren's syndrome (11.5%), rheumatoid arthritis (6.6%), mixed connective tissue disease (4.4%), systemic sclerosis (2.2%), polymyositis/dermatomyositis (1.3%), and vasculitis (0.4%). All 8 health concepts except RE and the physical and mental domains of SF-36 correlated with the total scores of SSC-J independent of other CVDs (Table 2), and the correlation coefficients of each health concept of SF-36 with the total scores of SSC-J were similar between SLE patients with other CVDs and those without. Nevertheless, the correlation coefficients of some mental components (SF, RE, and MH) appeared to

be lower in SLE patients with other CVDs than in those without other CVDs.

Therefore, among SLE patients without other CVDs, the correlations between SSC-J scores and each health concept were balanced throughout physical and mental concepts; however, among SLE patients with other CVDs, these correlations in mental concepts were weaker. This result suggests that SSC-J is not suitable for accurately evaluating mental aspects only when SLE patients are complicated by other CVDs. A limitation of this analysis is that the frequency of overlapped RA is higher than the previous reports which is ~1% of SLE.²⁷ These possible overdiagnosis might be derived from the high frequency of anti-CCP antibody in SLE patients.²⁸

Among the various QOL measurement tools, SSC-J has a feature to identify the symptoms reducing the QOL of each patient, which neither SF-36 nor LupusPRO have. In the present study, painful muscles, shortness of breath, and painful joints markedly affected the PCS of SF-36, fatigue, mood changes, and muscle weakness had a major effect on the MCS of SF-36, and fatigue, muscle weakness, and poor wound healing had a significant effect on the HRQOL of Japanese LupusPRO. This characteristic of SSC-J to be able to identify the symptoms reducing the QOL is useful for discussing how to improve patients' QOL.

SSC-J will be useful for evaluating the symptoms of patients at every clinic visit.

As shown in Table 4, age, CS doses, and PGA were associated with SSC-J scores. Similar results were obtained with SF-36 and LupusPRO. A previous study reported that QOL decreased with age¹⁶. This was partly due to increases in the severity of muscle cramps, disturbed memory, and blue/purple stretch marks on the skin. Patients who received higher CS doses also had a slightly lower QOL. Symptoms such as plump cheeks/face, facial hair growth, and mood changes (all side effects of CS) appeared to reduce QOL. PGA correlated with SSC-J total scores. The strength of the subjective symptoms of skin rash, vulnerable skin, and sensitivity to sunlight in patients may exacerbate PGA (Table 5).

Conclusions

SSC-J appears to be a suitable tool for measuring the QOL of SLE patients as efficiently as SF-36 and Japanese LupusPRO.

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Supplemental material

Supplemental material for this article is available online.

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