

The Chinese version of the SLEQOL is a reliable assessment of health-related quality of life in Han Chinese patients with systemic lupus erythematosus

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Received: 24 April 2017 / Revised: 31 October 2017 / Accepted: 6 November 2017 / Published online: 22 November 2017
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Abstract To assess the health-related quality of life (HRQOL) of Han Chinese people with systemic lupus erythematosus (SLE) using a Chinese version of the Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQOL-C) and explore the factors influencing HRQOL of people with SLE. Participants were Han Chinese people with SLE. The SLEQOL-C and 36-item Short Form Health Survey (SF-36) were used to estimate the HRQOL. Disease activity was determined using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and fatigue using the Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F). Participant factors included age, gender, educational background, disease duration, erythrocyte sedimentation rate (ESR), and complement C3 and C4 levels. The results showed that higher SLEQOL-C scores correlated with lower SF-36 both measures are essential for HRQOL prediction. The SLEQOL-C scores were correlated with educational level, age, FACIT-F score, SLEDAI score, and ESR, which suggests that poor educational background, old-age, and increased fatigue, disease activity, and ESR might represent poor HRQOL. Although disease duration did not significantly correlate with the scores on the SLEQOL-C; those whose disease duration was 12–24 months had higher SLEQOL-C summary scores and physical functioning, symptoms, and treatment subscale scores than

did those whose duration was less than 6 months. The FACIT-F score, education level, age, disease duration, SLEDAI score, and ESR contributed to SLEQOL-C scores. The SLEQOL-C is reliable for assessing HRQOL of Han Chinese people with SLE. Fatigue, educational level, age, disease duration, ESR, and disease activity mainly influenced HRQOL of SLE patients.

Keywords Chinese · Health-related quality of life · SLEQOL · Systemic lupus erythematosus

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with variable multi-system involvement of unknown cause [1–3]. It is characterized by a relapsing-remitting course [4]. The natural progression of the disease as well as concomitant long-term administration of glucocorticoids and immunosuppressants can significantly influence the health-related quality of life (HRQOL) of patients. Therefore, people with SLE are likely to suffer from psychological as well as physical issues throughout the disease course. Although the survival rate of SLE has improved over the last few decades, the HRQOL of people with SLE has not [5]. Unfortunately, neither clinical and laboratory data nor measures of morbidity and mortality can entirely indicate the impact of the disease. According to the recommendation of the Systemic Lupus International Collaborating Clinics (SLICC) group, three factors should be present in a comprehensive description of SLE patients: disease activity, accumulated damage, and HRQOL. Thus, the degree of functional disability and overall HRQOL of people with SLE are essential for the complete assessment of this patient group [6].

HRQOL is a multidimensional concept that centers on the patient's overall perception of the impact of a certain illness

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and treatment on their functional, physical, social, and emotional well-being [7]. It is differentiated from other aspects of HRQOL, which often imply that the decrement in patients' HRQOL is specifically attributable to a decrease in health status [8]. Consequently, a comprehensive and reasonable assessment of people with SLE is important and should not only include fatigue, disease activity, and cumulative organ damage, but also HRQOL [8]. HRQOL has a profound impact on people with SLE and it is therefore important to ascertain which factors deteriorate or improve the HRQOL of these individuals [6].

Two types of measures are well suited to assessing HRQOL: generic questionnaires and disease-specific questionnaires. Generic questionnaires such as the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) [7], Health Assessment Questionnaire (HAQ) [9], General Health Questionnaire (GHQ) [10], EuroQol scale (EQ-5D) [11], and 20-Item Short Form Health Survey (SF-20) [12] were developed for the general population and may be used for all types of diseases. These generic measures are widely used and make it possible to compare the HRQOL among groups with different diseases, as well as healthy controls. Among the generic questionnaires, the SF-36 is the most commonly used measure for people with SLE [13]. It is effective and reliable in identifying the physical, psychological, and social effects of the disease on this group [14, 15].

In people with SLE, there is a strong heterogeneity of clinical manifestations as multiple systems and organs are usually involved. However, generic questionnaires are designed for the general population and not for people with SLE; which means that they often contain unnecessary items or miss issues pertinent to this group. In other words, the reliability and sensitivity of generic questionnaires might be inferior to those of disease-specific instruments. For this reason, it is important to utilize SLE-specific instruments when evaluating the HRQOL of patients with SLE. SLE-specific instruments, such as the Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQOL) [16], Lupus Quality of Life Questionnaire (Lupus QOL) [17], and SLE Symptom Checklist (SSC) [18], provide a comprehensive overview of the HRQOL of people with SLE, and include domains that are crucial to SLE. Given that they are specifically designed for people with SLE, they might be more sensitive to changes than generic instruments might be.

The SLEQOL, developed by Leong et al. in 2002 [16], is an SLE-specific HRQOL instrument that fully covers the physical and psychological aspects of the HRQOL of patients with SLE. Additionally, the Chinese version of SLEQOL (SLEQOL-C) is one of the first SLE-specific QOL instruments available in Chinese [19, 20]. The SLEQOL is regarded as a better indicator of the changes in HRQOL of patients with SLE when compared with the SF-36. In sum, it is obvious that a disease-specific questionnaire would be optimal for

measuring HRQOL of people with SLE. This study was the first to use the SLEQOL-C to evaluate the HRQOL of Han Chinese patients with SLE. The aim of this study was to determine the crucial factors affecting the HRQOL of people with SLE.

Materials and methods

Patient selection

From June 2008 to August 2015, the researchers approached 269 Han Chinese patients with SLE, 46 of which were illiterate or unwilling to participate. The response rate to the questionnaires was 82.9%. Thus, 223 people with SLE were enrolled in the survey. All participants were from the hospital wards or outpatient rheumatology clinic of the First Affiliated Hospital of Harbin Medical University. All participants fulfilled the 1997 American College of Rheumatology (ACR) classification criteria for SLE [21]. The questionnaires administered to each patient included the SLEQOL-C, SF-36, Systemic Lupus Erythematosus Disease Activity Index (SLEDAI), and Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F). The participant characteristics assessed included gender, age, educational background, disease duration, erythrocyte sedimentation rate (ESR), and complement C3 and C4 levels. All participants all gave their informed consent. The study protocol was approved by the Ethics and Research Committee of the First Affiliated Hospital of Harbin Medical University.

Quality of life assessment

HRQOL was assessed using the SLEQOL-C and SF-36. The SLEQOL-C assesses HRQOL in the past week and comprises 40 items that fall into six domains: physical functioning, activities, symptoms, treatment, mood, and self-image. The respondents are asked to rate each item on a 7-point scale ranging from 1 to 7 (including “not difficult at all” to “extremely difficult”; “not at all troubled” to “extremely troubled”; and “not at all often” to “extremely often”) [8]. The total score, which is the sum of the 40 item scores, ranges from 40 to 280. The higher the SLEQOL-C scores, the worse the self-perceived QOL. The SF-36 measures eight domains of HRQOL using 36 items: physical functioning (PE), role limitations due to physical problems (RP), role limitations due to emotional problems (RE), social functioning (SF), mental health (MH), energy/vitality (VT), body pain (BP), and general health perception (GH). For each domain, the scores were coded, summed, and transformed to range from 0 (worst) to 100 (best).

Disease activity assessment

Disease activity was assessed by a rheumatology specialist using the SLEDAI. The SLEDAI is a validated disease activity measure that covers both clinical symptoms and laboratory measures of SLE activity. It is a physician-rated index comprising 24 descriptions of disease activity, each of which is rated from 1 to 8 depending on the disease severity. The total SLEDAI score ranges from 0 (no activity) to 105 (maximum activity). Participants were divided into four groups according to their SLEDAI scores: no activity (0 to 4 points), mild activity (5 to 9 points), moderate activity (10 to 14 points), and severe activity (15 to 105 points) [5].

Statistical analysis

Descriptive data are presented as percentages and measurement data as means \pm SD. SAS version 9.1.3 was used to perform the statistical analysis. Spearman rank correlations were used to determine the relationships between the SLEDAI scores, SLEQOL-C scores, SF-36 scores, and participant characteristics. One-way analyses of variance (ANOVAs) were performed to identify possible influencing factors (age, educational background, ESR, and disease activity) associated with the SLEQOL-C. A multivariate linear regression analysis was then performed using a stepwise selection method, with entry and removal criteria of 0.10. Statistical tests were two-tailed, and the significance level was set at 5%, except for the multivariate linear regression, wherein 1% was used.

Results

General characteristics

Among the 223 Han Chinese participants who gave valid responses to the questionnaires, 209 were female (93.7%) and 14 were male (6.3%). Their ages ranged from 14 to 79 years ($M = 34.9 \pm 12.6$). The disease duration ranged from 1 to 120 months ($M = 22.26 \pm 34.7$). Of the participants, 17.13% received only a primary education or less (i.e., elementary school or no formal education), 63.54% had attained a secondary education (middle school or high school), and 19.34% had attained a post-secondary education (bachelor's degree or above).

The correlation analysis of SLEQOL-C scores

Correlation analysis of the SLEQOL-C and SF-36

Higher scores on the SLEQOL-C indicate poorer HRQOL while higher scores on the SF-36 indicate better HRQOL.

The mean scores on each of the SLEQOL-C and SF-36 domains are shown in Table 1. Based on the collected data, we constructed a correlation matrix between all domains of the SLEQOL-C and SF-36. As shown in Table 2, there were negative correlations among each of the SLEQOL-C and SF-36 domains, except for the self-image domain of the SLEQOL-C and PF domain of the SF-36. In other words, higher scores on the SLEQOL-C corresponded to poor HRQOL. Some individual domains of the SLEQOL-C showed strong negative correlations with the domains of the SF-36. The pairs with the highest coefficients were as follows: the physical functioning subscales of both scales; the SLEQOL-C PF and SF-36 BP; the SLEQOL-C summary score and VT; the symptoms subscale and VT; the symptoms subscale and SF; the SLEQOL-C summary score and MH; and mood subscale and MH. It indicated there was good agreement between the two measures.

Factors related to SLEQOL-C scores

A number of factors were tested for associations with the SLEQOL-C score, including age, gender, education background, disease duration, ESR, complement C3 and C4 levels, disease activity, and fatigue.

We found that education and FACIT-F score were correlated with the SLEQOL-C summary score and the scores on all six domains. Furthermore, the SLEDAI score and ESR were positively correlated with the SLEQOL-C summary score and some of the subscale scores. Moreover, age positively correlated with scores on the physical functioning subscale (Tables 3 and 4). Higher educational background and lower fatigue, disease activity, and ESR might, therefore, represent better HRQOL. Furthermore, elderly SLE participants reported the worst HRQOL.

Interestingly, the disease duration and complement C4 level did not have a significant correlation with the scores of SLEQOL-C.

Single factor analysis

We found that age, educational background, ESR, and disease activity were related to SLEQOL-C scores. Subsequently, we investigated the differences in SLEQOL-C scores among the different groups of these factors and according to disease duration. Compared to the no activity group and the mild or moderate activity group, the severe activity group had a significantly higher SLEQOL-C physical function score ($p < 0.05$) (Fig. 1a). The 12–24 months group had higher SLEQOL-C summary scores and physical functioning, symptoms, and treatment subscale scores compared to the less than 6 months group ($p < 0.05$) (Fig. 1b). We also found that, compared to the primary education or less group, both secondary education group and post-secondary education group had

Table 1 Descriptive statistics for SLEQOL-C and SF-36 scores

SLEQOL-C domains	Mean ± SD	SF-36 domains	Mean ± SD
Summary score	104.236 ± 40.380	PF	23.911 ± 4.967
Physical functioning	13.778 ± 8.626	RP	26.899 ± 36.085
Activities	23.35 ± 12.101	BP	67.165 ± 22.277
Symptoms	20.873 ± 9.857	GH	47.253 ± 21.866
Treatment	9.114 ± 4.755	VT	55.190 ± 22.188
Mood	10.563 ± 5.474	SF	70.886 ± 24.012
Self-image	26.557 ± 11.335	RE	4.089 ± 1.191
		MH	58.734 ± 18.065

SD, standard deviation; SLEQOL-C, Chinese version of Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire; SF-36, Medical Outcomes Study 36-item Short Form Health Survey; PF, physical functioning; RP, role physical; BP, bodily pain; GH, general health; VT, vitality; SF, social functioning; RE, role emotional; MH, mental health

lower SLEQOL-C summary scores as well as lower scores on the physical functioning and symptoms subscales ($p < 0.05$). Furthermore, the post-secondary education group had lower SLEQOL-C treatment, mood, and self-image subscale scores compared to the primary education or less group ($p < 0.05$), as well as a lower SLEQOL-C summary score and subscale scores in the treatment and self-image domains compared to the secondary education group ($p < 0.05$) (Fig. 1c). As shown in Fig. 1d, participants older than 60 years had higher SLEQOL-C mood subscale scores ($p < 0.05$). Participants with higher ESR had significantly higher subscale scores on

the physical functioning subscale than those with a normal ESR ($p < 0.05$) (Fig. 1e).

Stepwise multiple regression analysis

Our study showed that educational background affected the SLEQOL-C summary score and scores on the treatment, mood, and self-image subscales. Fatigue scores had a significant effect on the SLEQOL-C summary score and all six subscale scores. The SLEDAI scores were related to the symptoms subscale scores. We also found that ESR affected

Table 2 Correlations among each of the SLEQOL-C and SF-36 subscales

SF-36 domains		SLEQOL-C domains						
		Summary score	Physical functioning	Activities	Symptoms	Treatment	Mood	Self-image
PF	rho	-0.3825	-0.4203	-0.3918	-0.3931	-0.1822	-0.2097	-0.1076
	p	<.0001	<.0001	<.0001	<.0001	0.0074	0.002	0.1156
RP	rho	-0.3074	-0.1862	-0.3465	-0.3189	-0.1688	-0.1574	-0.1585
	p	<.0001	0.0062	<.0001	<.0001	0.0132	0.0209	0.02
BP	rho	-0.3785	-0.4004	-0.3344	-0.3553	-0.2624	-0.2604	-0.1513
	p	<.0001	<.0001	<.0001	<.0001	<.0001	<.0001	0.0269
GH	rho	-0.3130	-0.1746	-0.3132	-0.2957	-0.1967	-0.2113	-0.2129
	p	<.0001	0.0113	<.0001	<.0001	0.0042	0.0021	0.0019
VT	rho	-0.4521	-0.2959	-0.3668	-0.4307	-0.3445	-0.3566	-0.3114
	p	<.0001	<.0001	<.0001	<.0001	<.0001	<.0001	<.0001
SF	rho	-0.3469	-0.1739	-0.2839	-0.4235	-0.2216	-0.2092	-0.2399
	p	<.0001	0.0116	<.0001	<.0001	0.0012	0.0023	0.0005
RE	rho	-0.3057	-0.1318	-0.3216	-0.3597	-0.1493	-0.1664	-0.1876
	p	<.0001	0.05	<.0001	<.0001	0.0287	0.0146	0.0058
MH	rho	-0.4156	-0.1952	-0.3126	-0.3754	-0.2984	-0.4256	-0.3497
	p	<.0001	0.0043	<.0001	<.0001	<.0001	<.0001	<.0001

SLEQOL-C, Chinese Version of Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire; SF-36, Medical Outcomes Study 36-item Short Form Health Survey; PF, physical functioning; RP, role physical; BP, bodily pain; GH, general health; VT, vitality; SF, social functioning; RE, role emotional; MH, mental health; rho, Spearman correlation coefficient

Table 3 Factors related to SLEQOL-C scores

Factors	SLEQOL Score		Physical function		Activities		Symptoms		Treatment		Mood		Self-images	
	rho	p	rho	p	rho	p	rho	p	rho	p	rho	p	rho	p
SLEDAI score	0.15	<0.05	0.33	<0.0001	–	–	–	–	0.18	<0.05	–	–	–	–
Education	–0.26	<0.05	–0.22	<0.05	–0.15	<0.05	–0.23	<0.05	–0.26	<0.05	–0.19	<0.05	–0.23	<0.01
Age	–	–	0.14	<0.05	–	–	–	–	–	–	–	–	–	–
FACIT score	0.64	<0.0001	0.57	<0.0001	0.48	<0.0001	0.58	<0.0001	0.48	<0.0001	0.48	<0.0001	0.41	<0.0001
ESR	0.22	<0.05	0.42	<0.05	0.15	<0.05	0.2	<0.05	0.21	<0.05	–	–	–	–

“rho” –Standardized regression coefficients,“–” no data

both the physical functioning and symptoms subscale scores, disease duration affected symptoms scores, and age affected self-image scores (Table 5).

Discussion

The HRQOL of people with SLE is likely to be affected by their disease, and poor HRQOL might lead to an increase in disease severity [22]. Previous studies have demonstrated that the HRQOL of Chinese patients with SLE, assessed using the SF-36, was significantly inferior to that of healthy controls. Accurate and effective measures of assessing the HRQOL of patients with SLE are crucial [23, 24]. Guidelines by both the U.S. Food and Drug Administration and European Medicines Agency encourage researchers to employ patient-reported questionnaires when evaluating HRQOL [25, 26]. As previous studies have suggested, the SF-36 is a reliable and valid generic measurement of HRQOL for people with SLE [27], but it might not cover specific aspects of HRQOL for such patients [28]. Disease-specific instruments have consistently been shown to be more responsive than generic ones, as they include domains important for assessing the progress, extent of organ involvement, and response to treatment of specific diseases [29, 30]. Considering this, there is an increasing need

for a specific, valid method of assessing HRQOL of patients with SLE [30].

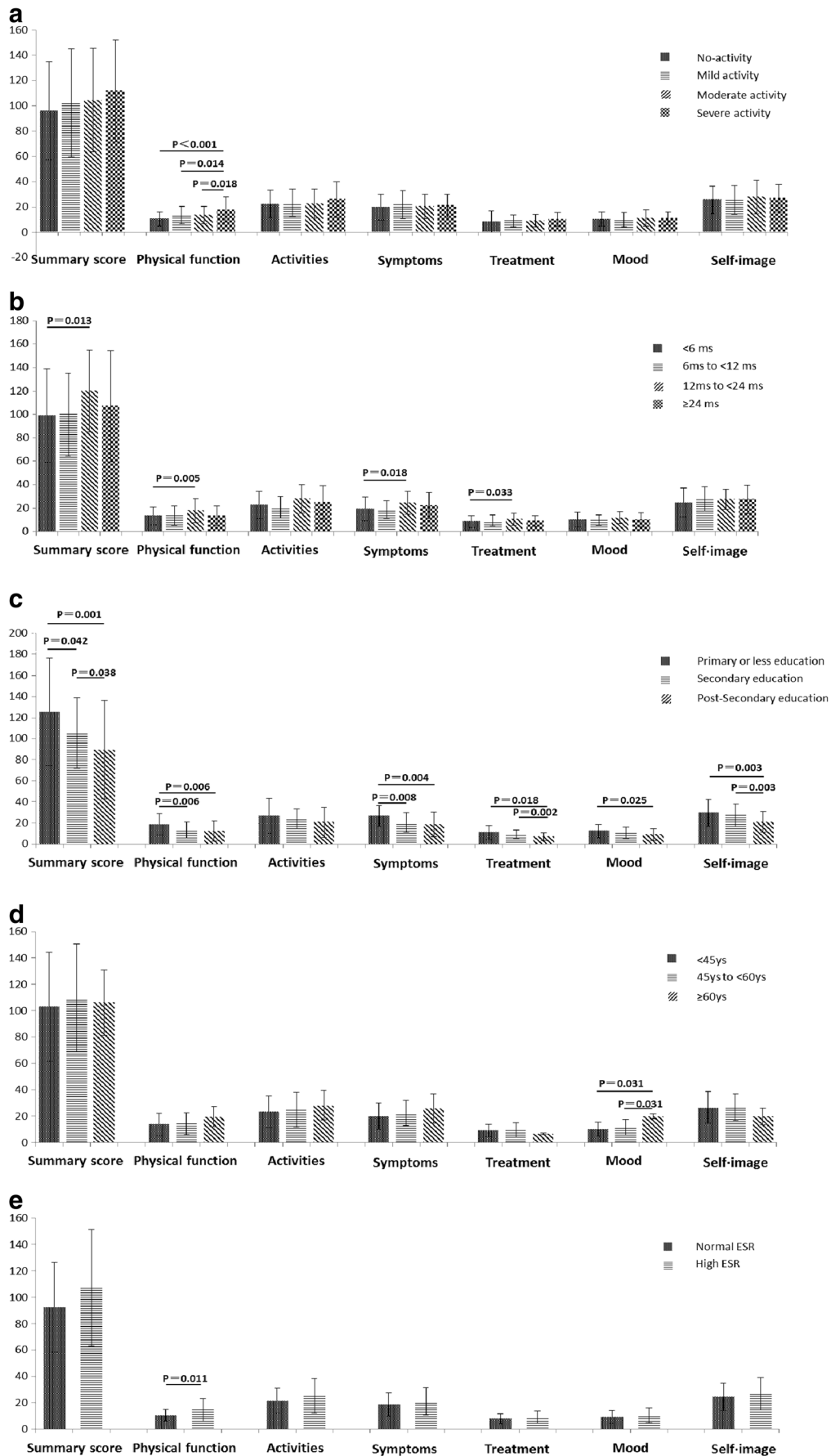
Currently, there are four known SLE-specific HRQOL instruments: the SLE Quality of Life Questionnaire (L-QOL), SSC, Lupus QOL, and SLEQOL. These instruments focus on the specific challenges and issues faced by patients with SLE, unlike generic instruments [8, 16–18]. The L-QOL is a 25-item questionnaire that assesses self-care, fatigue, and emotional reactions. The SSC is a 38-item checklist of disease- and treatment-related physical symptoms and is not a comprehensive assessment of HRQOL of patients with SLE. The Lupus QOL contains 34 items in eight domains, such as physical and emotional health. However, all three of these measures are only applicable to English-speaking patients; they remain unsuitable for Chinese-speaking patients.

In 2002, Leong et al. developed a new 40-item instrument in English containing items that rheumatologists and patients thought were important aspects of the HRQOL of people with SLE [16]. These items covered the physical, mental, and social domains of HRQOL. The measure was found to be valid for use in people with SLE in Singapore [16]. Subsequently, Kong et al., who were from the same study group, translated the English version of the SLEQOL into Chinese and found that the SLEQOL-C did not exhibit statistically significant differences from the English version. This suggests that the SLEQOL-C is accurate [19].

Table 4 Correlation analysis between SLEQOL-C and SLEDAI

SLEQOL-C domains	SLEQOL Score	SLEDAI Score	Correlation	P
Summary score	104.59 ± 40.9	12.74 ± 8.9	0.15	0.0228
Physical functioning	14.17 ± 8.4	12.74 ± 8.9	0.33	<0.0001
Activities	23.74 ± 12.2	12.74 ± 8.9	0.07	0.2714
Symptoms	20.76 ± 10	12.74 ± 8.9	0.07	0.2774
Treatment	9.14 ± 4.8	12.74 ± 8.9	0.18	0.0091
Mood	10.41 ± 5.58	12.74 ± 8.9	0.09	0.1862
Self-image	26.36 ± 11.4	12.74 ± 8.9	0.05	0.5

SLEQOL-C, Chinese Version of Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index



◀ **Fig. 1** **a** SLEQOL-C scores among different disease activity groups. The severe activity group had a significantly higher score on the physical function domain ($p < 0.05$). **b** SLEQOL-C scores among the different disease duration groups. The 12–24 months group had higher SLEQOL-C summary scores and scores on the physical functioning, symptoms, and treatment subscales compared to the less than 6 months group ($p < 0.05$). **c** SLEQOL-C scores among the different educational background groups. The secondary education group and the post-secondary education group had lower SLEQOL-C summary scores and scores on the physical functioning and symptoms subscales ($p < 0.05$). The post-secondary education group had lower SLEQOL-C subscale scores on treatment, mood, and self-image compared to the primary education or less group ($p < 0.05$), as well as a lower SLEQOL-C summary score and subscale scores on the treatment and self-image domains compared with the secondary education group, ($p < 0.05$). **d** SLEQOL-C scores among the different age groups. Participants older than 60 years had higher SLEQOL-C mood subscale scores ($p < 0.05$). **e** SLEQOL-C scores among the different ESR groups. A higher ESR was associated with significantly higher scores on the physical functioning subscale ($p < 0.05$). SLEQOL-C, Chinese version of the Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire; HRQOL, health-related quality of life

The Chinese population makes up about 19% of the global population, and it has a relatively higher incidence of SLE compared to other ethnic groups. Furthermore, numerous Chinese patients with SLE are not fluent in English [19]. However, until now, no studies have used the SLEQOL or SLEQOL-C on a sample of Han Chinese people with SLE. Thus, we administered the SLEQOL-C to assess the HROQL of this a sample, ensuring that the sample closely resembled the overall population of Chinese individuals with SLE by including a wide range of age groups, educational levels,

disease durations, and disease activities. At the same time, the SF-36, FACIT-F, SLEDAI, and a questionnaire assessing certain participant characteristics were administered to explore the factors influencing HRQOL of people with SLE.

Our study showed significant cross-sectional correlations between the six domains of the SLEQOL-C and the eight domains of the SF-36, except for between self-image and physical functioning. Given that the patients with the worst HRQOL also had the worst SLEQOL-C scores, we can say that the SLEQOL-C showed good construct validity.

Fatigue is a common clinical manifestation in patients with SLE, and more than 50% of participants felt excessively tired, regardless of their disease stage. Our results showed the SLEQOL-C scores positively correlated with the FACIT-F score, suggesting that fatigue was closely related to the HRQOL of patients with SLE. Sandor Balsamo et al. found that premenopausal SLE patients with lower disease activity tended to show increased fatigue and worse HRQOL compared to healthy controls [31]. Bruce et al. also reported that the fatigue severity of people with SLE was correlated with a poorer health status and that the factors associated with HRQOL had a greater influence on the severity of fatigue than did the disease activity [32]. Our research suggests that the SLEQOL-C can better able to reflect improvements in fatigue status among people with SLE, making it indispensable to the efforts to improve the HRQOL of people with SLE.

Although people with SLE have been consistently shown to have impaired HRQOL, the relationship between disease activity and HRQOL remains controversial. We found that SLEQOL-C scores positively correlated with SLEDAI scores,

Table 5 Stepwise multiple regression analysis

SLEQOL domain	Demographics	β	T	P
Physical functioning	FACIT-F	10.22272	2.17	0.033
	ESR	0.05069	3.24	0.0017
Activities	FACIT-F	0.51957	5.66	<0.001
Symptoms	Disease duration FACIT-F	0.06184	1.89	0.0615
	SLEDAI Score	0.34365	4.2	<0.0001
	ESR	-0.28205	-2.6	0.0108
Treatment	Education	0.05647	2.69	0.0087
	Education	-1.83204	-2.74	0.0074
	FACIT-F	0.20034	5.92	<0.0001
Mood	Education	-1.68363	-2.73	0.0202
	FACIT-F	0.16128	4.02	0.0001
Self-image	Age	-0.14656	-1.69	0.0936
	Education	-3.40176	-2.09	0.0391
	FACIT-F	0.30061	3.12	0.0025
Summary score	Education	-0.958976	-1.74	0.0854
	FACIT-F	1.97657	6.69	<0.0001

SLEQOL-C, Chinese Version of Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index; FACIT-F, Functional Assessment of Chronic Illness Therapy-Fatigue

indicating that a higher disease activity was related to worse physical functioning and worse HRQOL. Our results also showed that there was a positive correlation between SLEQOL-C scores and ESR, with an elevated ESR indicating worse physical functioning and lower HRQOL. A number of studies have indicated that HRQOL of people with SLE is significantly related to their disease activity. Hamdy Sliem et al. reported that, except for emotional limitations, all domains of the SF-36 were significantly correlated with SLE disease activity [33]. While the results of most previous studies are consistent with ours, they also differ in some aspects. Thumboo et al. reported that the HRQOL of people with SLE has a significant negative correlation with disease activity [34], whereas other studies found no significant correlations between the SLEDAI and measures of HRQOL [23, 35, 36]. These inconsistencies might be due to the different measurements of HRQOL and disease activity used in each study. Another potential explanation is that local factors and personality might have a more direct effect on patients' perception of HRQOL than the disease itself might have [37].

Previous studies have shown that education is correlated with HRQOL [24, 38]. In this study, we also found that a higher educational level was associated with a lower SLEQOL-C summary score and scores on the physical functioning, activities, symptoms, treatment, and mood subscales. Karlson et al. reported that coordinating education and counseling with medical care could improve disease outcomes for people with SLE [39]. Patients with higher educational levels might have a better understanding of the disease and are better at self-adjusting, adhering to regular follow-up appointments, adhering to medication, and adapting to the society and surrounding environment. At the same time, educational level to a certain extent is determined by social ranking and economic conditions, which also affect living conditions, choice to seek health care, and the convenience of seeking medical advice. All of these might indirectly or directly affect HRQOL.

In this study, we found that age and disease duration also influenced SLEQOL-C scores. The HRQOL of people with SLE might worsen with age due to changes in physiological and psychological factors. It also affects all health domains at an earlier age compared to people with other chronic diseases, such as hypertension, adult-onset diabetes mellitus, myocardial infarction, and depression [14]. Rinaldi et al. reported that in Italian people with SLE, HRQOL tended to decrease with age compared to in healthy controls [40]. However, Khanna et al. found that neither age (mean age 35.22 ± 11.15 years) nor disease duration (mean disease duration 5.62 ± 5.14 years) affected the HRQOL of people with SLE on any of the domains of the World Health Organization Quality of Life-Brief scale [41]. Although a few studies have shown that disease duration is not associated with HRQOL [42, 43], we believe that longer disease duration is accompanied by more adverse

effects from glucocorticoids and immunosuppressants, lower mood, worse symptoms, and higher disease costs.

The limitations of the present study are as follows. First, we only reported some of the many factors that may affect HRQOL; in particular, we might have failed to include factors of potential significance, such as patients' income, marital status, mood, and organ damage. Second, our study only evaluated patients at a single point in time. A longer period of follow-up observation is necessary to show the deterioration of HRQOL of people with SLE over time and to determine the changes in the relationship between HRQOL and other factors over time.

Conclusions

In summary, our study indicated that the SLEQOL-C is a useful measure for evaluating the HRQOL of Chinese people with SLE. Furthermore, fatigue, educational level, age, disease duration, ESR, and disease activity were shown to be the main influencing factors of HRQOL of patients with SLE. The study provided a reliable assessment of HRQOL for Han Chinese people with SLE and can provide clinical guidance for the treatment and prognosis of the disease.

Author contributions Hai-Zhi Jiang, Zhi-Guo Lin, Hong-Juan Li, and Yi-Fang Mei conceived and designed the experiments; Hai-Zhi Jiang, Zhi-Guo Lin, Hong-Juan Li, Qing-Du, Wei-Tian, Shu-Ya Wang, Shang-Qi Guan, and Yi-Fang Mei performed the experiments; Hong-Juan Li and Shu-Ya Wang analyzed the data; Hai-Zhi Jiang and Shu-Ya Wang wrote the paper. Hai-Zhi Jiang and Zhi-Guo Lin contributed equally to this article. Funding information This research was supported by grants from the Education Department of Heilongjiang Province (grant number 12531239).

Compliance with ethical standards

Conflicts of interest The authors declare that no competing interests exist.

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