Clin Rheumatol (2016) 35:617–622
DOI 10.1007/s10067-015-2930-1

ORIGINAL ARTICLE

Health-related quality of life assessed by LupusQoL questionnaire and SF-36 in Turkish patients with systemic lupus erythematosus

Sibel Yilmaz-Oner[1] · Can Oner[2] · Fatih Mert Dogukan[3] · Toklong Filam Moses[3] · Kubra Demir[3] · Nazar Tekayev[3] · Pamir Atagunduz[1] · Serhan Tuglular[4] · Haner Direskeneli[1]

Received: 29 November 2014 / Revised: 22 March 2015 / Accepted: 23 March 2015 / Published online: 7 April 2015

Abstract The LupusQoL is a disease-specific health-related quality of life (HRQoL) measure for patients with lupus. We conducted this study to compare the efficiency of LupusQoL-TR (validated Turkish version of the LupusQoL questionnaire) with the 36-item Short-Form Health Survey (SF-36), a generic quality of life (QoL) scale, in Turkish patients with lupus. Both questionnaires were conducted at a single visit to the clinic. Disease activity was measured with the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI). Associations between the LupusQoL-TR and SF-36 domains were examined while also examining age, disease duration, and disease activity for each questionnaire. Descriptive statistics, Spearman's correlation coefficients, and Students *t* test were performed to analyze the data. A total of 113 consecutive patients with lupus (F/M 108:5, mean age 40.6±11.9 years, mean disease duration 8.5±7.0 years) were included, and 69 % of these were active. The median SLEDAI score was 2 (0–24), the mean global LupusQoL-TR score was 60.9±23.3, and the mean SF-36 score was 41.2±9.0. There was a significant correlation between LupusQoL-TR and SF-36 mean scores (r=0.83; p<0.001). QoL assessed by LupusQoL-TR and SF-36 did not correlate with disease activity (r=−0.11; p=0.244 and r=−0.03; p=0.721, respectively). LupusQoL-TR and SF-36 questionnaires were beneficial instruments in evaluating HRQoL in Turkish lupus patients. However, LupusQoL-TR and SF-36 were not associated with SLEDAI scores, which suggested that QoL might be affected by other factors besides disease activity, especially in clinically inactive or mildly active patients.

Keywords LupusQoL-TR · Quality of life · SF-36 · Systemic lupus erythematosus

✉ Sibel Yilmaz-Oner
sibely113@mynet.com

[1] Department of Rheumatology, School of Medicine, Marmara University, 34890, Pendik Istanbul, Turkey

[2] Department of Family Medicine, School of Medicine, Istanbul Bilim University, Istanbul, Turkey

[3] School of Medicine, Marmara University, Istanbul, Turkey

[4] Department of Nephrology, School of Medicine, Marmara University, Istanbul, Turkey

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that may involve multiple organs and/or systems. SLE is characterized by relapses and remissions. The new treatment strategies developed for lupus over recent decades have improved survival of patients significantly, and the assessment of health-related quality of life (HRQoL) has became an important outcome measure for patients with lupus [1]. The Outcome Measures in Rheumatology (OMERACT) IV consensus recommended that for both randomized clinical trials and longitudinal observational studies, the outcomes should be measured in terms of disease activity and damage in all organ systems, as well as by HRQoL and adverse events [2]. The Medical Outcomes Study Short-Form 36 (SF-36) is a generic measure, which is mostly used in a variety of chronic diseases, such as SLE. Physical (PCS) and mental health (MCS) components including eight domains of physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE), and mental health (MH) are present in SF-36 [3]. It has been recommended as the instrument to measure quality of life in patients with SLE by the Systemic Lupus International Collaborating Clinics Group (SLICC) [1]. The SF-36 is a valid

and reliable tool that identifies the physical, psychological, and social influence of the disease on patients with SLE [4, 5]. However, longitudinal studies that assessed HRQoL of patients with SLE have shown that SF-36 is not sensitive to change when administered biannually or yearly [6, 7]. It has also been suggested that some important issues for patients with SLE (such as sleep, sexual function, infertility, and body image) are absent from the generic measures, such as SF-36 [8, 9]. From this point of view, many SLE-specific HRQoL measures have been developed over the past decades [8, 10–12].

LupusQoL is a disease-specific measure that was developed and validated in the UK [8]. It has been shown to have good internal reliability, good test-retest reliability, and good concurrent validity with the comparable domains of SF-36 [8]. The questionnaire is patient derived, contains unique items, and provides a profile of patients' HRQoL, all of which distinguish it from existing lupus-specific measures [8]. There are studies in the literature that examine the correlation of LupusQoL with disease activity and the sensitivity of the questionnaire in determining disease activity changes (responsiveness) [13, 14]. McElhone et al. showed that LupusQoL provides additional information to the clinical indices of activity and damage [15]. Devilliers et al. investigated the responsiveness of the SF-36 and LupusQoL questionnaires and suggested that the LupusQoL may be more responsive than SF-36 in capturing changes in patients with SLE [16].

Until recently, Turkish lupusPRO was the only validated disease-specific questionnaire in Turkey for patients with SLE [17]. However, LupusQoL has been adapted and validated for Turkish patients with SLE by Pamuk et al. (LupusQoL-TR), who showed that the scale is an acceptable patient-reported outcome measure and a useful tool to assess HRQoL in Turkish patients [18]. The objectives of our study were to assess the value of the disease-specific LupusQoL-TR questionnaire and to compare it with a general quality of life (QoL) scale, SF-36, in another cohort of Turkish patients with SLE.

Material and methods

Consecutive patients with SLE who were being followed up at the rheumatology outpatient clinics of Marmara University, School of Medicine, Istanbul, Turkey, were invited to participate in this study during their routine attendance between January and December, 2013. All patients fulfilled the American College of Rheumatology (ACR) 1997 updated and revised classification criteria for lupus [19]. Demographic (age, sex, marital status, educational status, working status) and clinical information (a complete history, duration of SLE, disease activity, physical examination) was recorded for each patient, and also, laboratory tests were measured during the enrollment. The disease duration was calculated from the time when the patients' SLE was first diagnosed to the enrollment of the patients to the study. The laboratory and immunologic tests included complete blood count; blood urea nitrogen; creatinine; liver function tests; complete urinalysis; erythrocyte sedimentation rate; C-reactive protein; anti-nuclear antibody (ANA); anti-double-stranded DNA antibody (anti-dsDNA); and anti-Sm, anti-Ro (SSA), and anti-La (SSB) autoantibodies. Disease activity was assessed using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) [20]. The SLEDAI scores range between 0 and 105: 0=no activity, 1–5=mild activity, 6–10=moderate activity, 11–19=high activity, and ≥20=very high activity. Physician's global assessment (PGA) scores ranging from 0 to 3 were also used to evaluate disease activity. A PGA score of "0" means inactive, "1" mild, "2" moderate, and "3" high disease activity.

To rule out bias that could result from patients' differing education levels, all patients were asked to complete both the LupusQoL-TR and the SF-36 questionnaires with the help of a study nurse on the visit day. The LupusQoL is a specific HRQoL questionnaire that consists of eight domains with 34 items [8]. These domains are physical health, pain, planning, body image, burden to others, intimate relationships, emotional health, and fatigue. Each question of LupusQoL-TR has five different answer options, which are scored as follows: all of the time=0 point, most of the time=1 point, a good bit of the time=2 points, occasionally=3 points, and never=4 points. The minimum score for each of the eight domains is 0 and the maximum is 100 [8]. Scores of SF-36 range between 0 and 100; 0 means the worst QoL and 100 means the best [21].

The comparable domains of LupusQoL-TR and SF-36 are physical health and PF, emotional health and MH, fatigue and VT, and pain and BP [8]. The other four domains of both scales were accepted as noncomparable domains.

This cross-sectional study was approved by the local ethics committee, and all participants gave written informed consent.

Statistics

Means (SD), medians [interquartile ranges (IQR)], and/or frequency counts were the descriptive statistics used to summarize patients' data. Comparisons of two continuous variables were performed using independent and paired Students *t* test. The mean scores for all comparable and noncomparable LupusQoL-TR and SF-36 domains were analyzed. The correlation of the four comparable domains of LupusQoL-TR and SF-36 was done using Spearman's correlation coefficient test. For the four noncomparable domains of the LupusQoL-TR,

Spearman's correlation coefficient test was performed between each domain with both the PCS and MCS of the SF-36. SPSS version 16.0 was used to analyze the data. All *p*-values <0.05 were taken as significant.

Results

Patient characteristics and disease activity

One hundred thirteen patients participated in the study. Each completed the LupusQoL-TR and SF-36 questionnaires, and the demographic and clinical data were also collected on the day of the clinic visit. The patients' characteristics are summarized in Table 1.

Seventy-eight (69 %) patients had active disease: of these, 40 (35.4 %), 28 (24.8 %), 8 (7.1 %), and 2 (1.8 %) had mild, moderate, high, and very high disease activity according to the SLEDAI scoring, respectively. Low-dose steroids (less than or equal to 5 mg prednisolone or 4 mg methylprednisolone) were used by 47 %, high-dose steroids by 19 %, hydroxychloroquine by 76 %, and immunosuppressive agents by 57 % (16 patients were on methotrexate, 4 leflunomide, 28 azathioprine, 16 mycophenolate mofetil, 2 cyclophosphamide, and 3 rituximab).

Table 1 Patients' demographic and clinical characteristics

Demographic characteristics		*n* (%)
Sex	Female	108 (95.6)
Age (years) (mean) (SD)		40.6±11.9
Marital status	Married	93 (82.2)
	Single	20 (17.8)
Employment status	Unemployed	87 (77)
	Working	26 (23)
Disease duration (years) (median) (IQR)		6 (0.25–35)
Education (years) (mean) (SD)		7.6±4.3
Clinical characteristics (ACR criteria)		*n* (%)
Malar rash		49 (43.4)
Discoid rash		15 (13.3)
Photosensitivity		75 (66.4)
Oral ulcers		40 (35.4)
Arthritis/arthralgia		80 (70.8)
Serositis		15 (13.3)
Hematological disease		68 (60.2)
Renal disease		42 (37.2)
Central nervous system disease		6 (5.3)
ANA positivity		112 (99.1)
Anti-ds-DNA, Sm, or phospholipid antibody (+)		61 (54)
SLEDAI (median) (IQR)		2 (0–24)
PGA (median) (range)		1 (0–3)

SLEDAI SLE disease activity index, *PGA* patient global assessment

LupusQoL-TR and SF-36

The mean scores for the SF-36 and LupusQoL-TR were 41.2 ±9.0 and 60.9±23.3, respectively. The mean scores for eight domains of both SF-36 and LupusQoL-TR measures are presented in Table 2. The PCS and MCS scores and mean score of each domain of SF-36 were <45. The LupusQoL-TR scores were higher than the SF-36 scores for each of the comparable domains (mean scores: physical health/physical function, 62.6 ±26.4/43.4±11.4, $p<0.001$; emotional health/MH, 60.3± 30.1/40.8±12.8, $p<0.001$; pain/BP, 61.5±28.4/42.1±12.2, $p<0.001$; and fatigue/VT, 56.3±28.2/44.7±11.1, $p<0.001$). In our study group, in the LupusQoL-TR, *body image* was the least affected (mean±SD 72.6±26.9) and *burden to others* was the most affected domain (mean±SD 52.5±30.0). The mean scores of LupusQoL-TR were >60 in five domains (physical health, emotional health, pain, planning, body image) and <60 in three domains (fatigue, intimate relationships, and burden to others).

We also evaluated correlations between QoL, age, disease duration, and disease activity as assessed by SLEDAI and found that there was no significant correlation between the mean scores of questionnaires and these parameters in our study group (Table 3).

The mean scores of LupusQoL-TR and SF-36 were significantly correlated ($r=0.83$, $p<0.001$). Correlations between comparable domains of SF-36 and LupusQoL-TR domains were also examined, and the results are summarized in Table 2. There was a strong correlation between comparable domains of instruments. Noncomparable domains of LupusQoL-TR were analyzed in terms of correlation with PCS and MCS. Although not as strong as comparable domains, significant correlations were also found between body image, planning,

Table 2 Descriptive statistics and correlation coefficient for SF-36 and LupusQoL-TR domains

LupusQoL-TR domains	Mean (SD)	SF-36 domains	Mean (SD)	*r*	*p* value
Comparable					
Physical health	62.6±26.4	PF	43.4±11.4	0.69	<0.001
Emotional health	60.3±30.1	MH	40.8±12.8	0.69	<0.001
Pain	61.5±28.4	BP	42.1±12.2	0.62	<0.001
Fatigue	56.3±28.2	VT	44.7±11.1	0.63	<0.001
Noncomparable					
Planning	62.8±32.3	SF	41.8±13.2		
Intimate relationships	54.3±39.0	GH	39.5±11.4		
Burden to others	52.5±30.0	RE	40.0±13.1		
Body image	72.6±26.9	RP	41.1±12.3		
		PCS	40.4±10.6		
		MCS	42.0±11.6		

Table 3 Correlations between quality of life, age, disease duration and disease activity

	LupusQoL-TR *r* (*p*)	SF-36 *r* (*p*)
Disease activity (SLEDAI)	−0.11 (0.244)	−0.03 (0.721)
Age (year)	−0.13 (0.171)	−0.16 (0.076)
Disease duration (year)	−0.08 (0.355)	−0.16 (0.079)

intimate relationships, burden to others, and summary scores of SF-36 (Table 4).

Discussion

As a generic instrument, SF-36 may not have adequate sensitivity to assess items and domains that relate more specifically to patients with SLE; therefore, different disease-specific questionnaires have been developed and validated for these patients. LupusQoL is one of the developed and validated disease-specific HRQoL measures for adults with lupus [8].

In this study, we evaluated HRQoL in Turkish patients with SLE using the SF-36 and LupusQoL-TR questionnaires. We found decreased HRQoL in our cohort of patients with lupus who were assessed using both questionnaires, similar to previous studies [4, 22, 23]. We observed that the comparable domains of both questionnaires correlated well and each noncomparable domain of the LupusQoL-TR was correlated with both PCS and MCS, which was also in line with previous studies [8, 13, 14]. LupusQoL and SF-36 were shown to be equivalent in assessing HRQoL over time in patients with SLE [13]. All domains of LupusQoL-TR and SF-36 were low and consistent with impaired QoL, especially burden to others, intimate relationships, and fatigue in the LupusQoL-TR. In our study, the most impaired domain in LupusQoL-TR was burden to others, similar to the results of Garcia et al. [14]. A study by McElhone et al. likewise indicated that fatigue, physical health, and burden to others were the most impaired domains. The authors also reported that the burden to others domain had not been assessed in other HRQoL instruments, and thus, this domain might contribute to new intervention strategies that aim to improve QoL in lupus [15]. The least impaired domain was body image, and when we compared patients who had skin involvement with the others, there were no significant differences, which suggests that the body image could be affected by different aspects of the disease.

Table 4 Correlation between noncomparable LupusQoL-TR domains and SF-36 summary scores

LupusQoL-TR domains	SF-36 PCS		SF-36 MCS	
	r	*p*	*r*	*p*
Body image	0.43	<0.001	0.60	<0.001
Planning	0.65	<0.001	0.58	<0.001
Intimate relationships	0.43	<0.001	0.31	<0.001
Burden to others	0.43	<0.001	0.42	<0.001

In agreement with other studies that addressed HRQoL in patients with SLE, none of the LupusQoL-TR domain scores was associated with disease duration in our study [24, 25]. However, there are studies that indicate an association between disease duration and physical-MH, emotional role, and QoL, as assessed using SF-36 [26]. Patients with SLE form a heterogeneous group, so these disagreements between outcomes may result from a different disease course and demographic characteristics of patients who participated in other studies.

In our cohort, HRQoL assessed using both of the questionnaires did not correlate with SLEDAI scores. There are controversial results in the literature regarding the association of disease activity with QoL. Touma et al. showed a small to moderate responsiveness of SF-36 and LupusQoL due to a significant clinical change in disease activity [13]. The authors emphasized that the cross-sectional study design, which measured HRQoL at yearly intervals, was responsible for the discrepancy between QoL and disease activity. There are also studies that suggest that if HRQoL is measured at shorter intervals of 1, 3, and 6 months, the correlation between the disease activity and HRQoL may be more prominent [27–29]. McElhone et al. found impairment of some LupusQoL domains that were associated with disease activity [15]. Shen et al. showed that the total SF-36 score was affected by disease activity in both direct and indirect ways [30]. Nonetheless, Kuriya et al. [6] and Gladman et al. [31] emphasized that when SF-36 was used to assess cross-sectionally, it reflected the fibromyalgia presence rather than disease activity and damage. In patients with established disease, SF-36 scores are not affected by disease activity, steroids, or damage [6]. Devilliers et al. investigated the responsiveness of the SF-36 and LupusQoL questionnaires in a cohort of 185 patients with SLE and suggested that the specific and generic questionnaires seem to be complementary. The authors proposed that the generic questionnaire may be useful in revealing worsening symptoms and the LupusQoL may be more responsive in capturing changes in patients with SLE whose health status is improving [16].

Our study is the second to use the LupusQoL-TR questionnaire in Turkish patients with SLE. With the exception of planning, all domains of LupusQoL-TR in the first study were found to be sufficient at discriminating between active and inactive patients, which was different from our study. In the present study, the questionnaire was discriminative in all domains except for intimate relationship and emotional health in the group with high SLICC-ACR scores. The *pain* and *fatigue* domains were the most affected, and the least impaired domain was body image in the validation study. The burden to

others domain was not impaired in our group as much as it was in the validation study of Pamuk et al. [18].

Our study has some limitations arising from its cross-sectional design. Our patients were assessed in only one visit to the clinic, and as such, we measured QoL just once; therefore, we were not able to examine relationships, changes of disease activity, or QoL outcomes (responsiveness) over time. The associations of QoL and damage were not assessed in this study, because the patients' damage data was missing. The patients' comorbidities were not evaluated in this study, which may also affect HRQoL. Another limitation of the study may be the mild to moderate disease activity of our patients (median SLEDAI=2), and this could explain the lack of association with QoL measurements. Therefore, our results may not be valid for patients with moderate to high disease activity. Jolly M et al. reported lower LupusQoL scores and higher SLEDAI scores than Garcia et al. Garcia et al. suggested that the difference in the LupusQoL scores was due to higher SLEDAI scores (SLEDAI-2 K score was 4) in the cohort of Jolly M et al. [14, 32].

In conclusion, the LupusQoL-TR and SF-36 questionnaires were beneficial instruments in evaluating HRQoL of Turkish patients with lupus. However, LupusQoL-TR and SF-36 were not associated with SLEDAI scores, suggesting that QoL might be affected by other factors besides disease activity in clinically inactive or mildly active patients.

The usefulness of LupusQoL-TR should be further assessed in patients with moderate to high disease activity and at shorter intervals.

Acknowledgments The authors would like to thank Mary Gawlicki and Lee-Suan Teh for supplying the validated Turkish version of the LupusQoL-TR and permitting us to use this copyrighted questionnaire. We also would like to thank David Chapman for the language editing of the article.

Disclosure None.

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