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Translation, cultural adaptation and validation of the Systemic Lupus Erythematosus Activity Questionnaire (SLAQ) in a cohort of Italian systemic lupus erythematosus patients

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Introduction: The Systemic Lupus Erythematosus Activity Questionnaire (SLAQ) is a patient-reported instrument for the assessment of disease activity in systemic lupus erythematosus (SLE). The aims of the present study are translation, cultural adaptation and validation of an Italian version: the SLAQit. **Methods:** The process of translation and cultural adaptation followed published guidelines. SLAQit was pretested in a group of 35 SLE patients to evaluate acceptability, comprehension and feasibility. Internal consistency, test–retest validity and external validity were tested on consecutive SLE patients attending the clinic. **Results:** In total, 135 SLE patients were enrolled in this study. The pilot test provided a 99.9% response rate and demonstrated feasibility and comprehensibility of the questionnaire. A good internal consistency was found among the three components of the score (SLAQ score, numerical rating scale (NRS), patient global assessment question (PGA); $\alpha = 0.79$). SLAQit showed very high reliability (test–retest $\alpha > 0.8$). NRS and PGA showed a strong positive correlation with both Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) ($p = 0.002$ and $p < 0.001$, respectively) and European Consensus Lupus Measurement (ECLAM) scores ($p = 0.01$ and $p < 0.001$, respectively), while the SLAQ score did not. A significant agreement was observed between the physician's intention to treat and both the NRS and PGA scores, while no significant association was reported with the SLAQ score. **Conclusions:** SLAQit was demonstrated to be a reliable and valid instrument for self-assessment of disease activity in SLE patients. *Lupus* (2018) **27,** 1735–1741.

Key words: Patient-reported outcomes; SLAQ; systemic lupus erythematosus

Introduction

Assessment of disease activity is one important task in systemic lupus erythematosus (SLE) management and several activity indices have been developed, validated and are used in research, clinical trials and clinical practice.[1] All these indices assess disease activity based on clinical and laboratory data collected by the physician during patients' evaluation.

Literature data, however, have clearly shown that there is a discordance between physicians and patients in the assessment of disease activity.[2] This discordance may impact on patients' adherence to treatment, assessment and, in the end, may impact on outcomes.

Patient-reported outcomes (PROs) have gained increasing relevance in the assessment of rheumatic diseases since they are able to provide additional information on important issues such as health-related quality of life, fatigue and other subjective complaints that are not adequately captured by the physician-driven evaluation. Moreover, patient-administered questionnaires allow large amount of data to be collected with significant saving of time and costs.[3–5]

The Systemic Lupus Erythematosus Activity Questionnaire (SLAQ) is a patient-reported instrument for the assessment of disease activity in SLE.[6,7]

The SLAQ is based on three components: (i) a patient global assessment question (PGA); (ii) a list

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of questions on SLE symptoms (SLAQ score); and (iii) a numerical rating scale (NRS).

PGA asks about the presence and severity of lupus activity over the past 3 months; the possible answers are: a) no, no flare; b) yes, mild flare; c) yes, moderate flare; d) yes, severe flare.

The SLAQ score includes a list of questions on 24 symptoms including constitutional, mucocutaneous, articular, respiratory, gastrointestinal, neuropsychiatric and gastrointestinal manifestations. For each symptom, patients are asked to choose between four options: a) mild; b) moderate; c) severe; d) no symptom. The items are weighted according to their clinical importance and grouped into 17 categories; each item can be scored from 0 to 3 according to the severity of the symptom. The final SLAQ score sum can range from 0 to 47.

NRS rates the disease activity over the past 3 months on a scale of 0–10 (were 0 means no activity and 10 is high activity).

The aims of the present study are the translation and the cultural adaptation of the instrument for an Italian-speaking population and the validation of the instrument in a large Italian cohort.

Methods

Translation and pilot study

The process of translation and cultural adaptation followed published guidelines.[8]

In detail, the original SLAQ questionnaire was translated using a forward/backward protocol. The SLAQ questionnaire was independently translated into Italian by two bilingual translators (GT and LM) with different backgrounds whose mother tongue was the target language (Italian) (versions T1 and T2). A third researcher (CT) produced a first common translation obtained by a merge of T1 and T2; a written report of the synthesis process, each of the issues addressed and how they were resolved was also prepared. The Italian version was then translated back into English by two professional translators (WD and MR) who had not participated in the first English–Italian translation process. The back-translations (BT1 and BT2) were produced by two native English speakers who were unaware of the concepts explored and had no medical background. The two back-translated questionnaires were then compared with the original English language questionnaire in order to assess the validity of the Italian translation. The comparison was carried out by one researcher (CT) and two native English speakers. The final phrasing of the SLAQit questionnaire was negotiated by a committee composed of two experienced rheumatologists (ADR and MM), the four translators and one patient. The committee reviewed all the translations and reached a consensus on discrepancies. The following aspects were evaluated: semantic equivalence, idiomatic equivalence, experiential equivalence and conceptual equivalence.

The final version of the questionnaire was pretested in a group of 35 consecutive SLE patients attending a routine visit at our outpatient clinic in February 2016, to evaluate acceptability, comprehension and feasibility.

Validation

Patients

Consecutive patients fulfilling the 1997 American College of Rheumatology (ACR) criteria for SLE[9] and attending the outpatient clinic or the inpatient wards of the Rheumatology Unit of the University of Pisa between March 2016 and July 2016 were enrolled.

The only inclusion criterion was that patients had to be 18 years of age or older. Exclusion criteria included dementia, neurological deficit, or linguistic barriers that could significantly compromise comprehension of the questionnaire.

At enrollment, the SLAQit questionnaire was self-administered in the waiting room before attending the routine visit. A rheumatologist blinded to the SLAQit results performed the routine visit and recorded the disease activity and organ damage as assessed by the European Consensus Lupus Measurement score (ECLAM), the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) score, respectively. A physician's intention to treat disease activity by either introducing a new drug or increasing the dosage of an ongoing therapy was considered a surrogate index for the physician's judgement on disease activity. Concomitant medications and comorbidities were also recorded.

Because data were already collected as part of our routine clinical practice, the study protocol was retrospectively approved by The Comitato Etico di Area Vasta Nord Ovest Institutional Review Board (protocol number 6331) and each patient provided written informed consent.

Statistical analysis

For the descriptive analysis, continuous values are reported as mean or median values and standard

deviation as appropriate; categorical variables are expressed as proportions.

Internal consistency between the three components of the score was evaluated by Cronbach's alpha; a Cronbach's alpha > 0.70 was considered acceptable.

The external validity was tested toward validated activity indices (SLEDAI and ECLAM) scored by a physician blinded to the SLAQ results. Spearman's rank correlations were carried out; levels of statistical significance were defined at 5% ($p < 0.05$).

For the test–retest validity assessment, in a subgroup of 33 patients the questionnaire was administered twice at 2-week intervals; the second administration was by telephone interview within 1 month after their visit. Reliability and agreement were evaluated respectively by means Spearman's rank correlation, ρ, and Lin's concordance correlation coefficient, ρ_c.[10]

The expected value for the Spearman correlation and Lin's concordance correlation coefficient was evaluated; given the limited sample size of our study sample we expect that good reliability and agreement for value of about 0.80 or more.

Statistical significance was defined at 5% ($p < 0.05$).

Results

Cohort description

In total, 135 SLE patients were enrolled in this study. The first 35 patients were enrolled in the pilot study, while the following 100 patients constituted the validation cohort. Epidemiological and cumulative clinical characteristics of the pilot sample and of the whole cohort are reported in Table 1. No statistically significant differences were observed between the pilot sample and the validation cohort.

In detail, the validation cohort was composed predominantly of women (91.8%), with a mean age of 43.3 years and a long disease duration (mean 14.3 years).

Overall, the sample presented a low disease activity (median SLEDAI score of 2, interquartile range 0–4); joint and skin manifestations were the most frequent symptoms at enrollment (present in 15% and 12% of patients respectively); some patients also presented renal, hematological and neuropsychiatric features (8%, 7.3% and 2.6% respectively). As far as organ damage is concerned, 53.3% of patients had at least one item of organ damage in accordance with the SLICC/ACR DI score (median 1, interquartile range 1–3).

No statistically significant differences in term of disease activity and organ damage were recorded in the pilot cohort with respect to the validation cohort.

Questionnaires administration

The pilot test provided a 99.9% response rate, suggesting that the SLAQit questionnaire has a very good level of acceptability. Feasibility was also good as the mean time to complete the test was 4.6 ± 2.3 minutes (range 1–10), 100% of the patients stated that they understood the scope of the SLAQit and 67.5% said that they had no problems regarding comprehension of the content.

The results of the SLAQit administration in the pilot sample together with the whole cohort are reported in Table 2. The questionnaire results showed a clear skewness to the lower scores and 5.2% of patients scored zero in the SLAQ score, 20.7% in the NRS score and 65.9% in the PGA score. The 75% quartile was 18, 6 and 1 for the SLAQ score, NRS and PGA, respectively.

A good internal consistency was found between the three components of the score (NRS vs PGA vs SLAQ score; $\alpha = 0.79$).

SLAQit showed good reliability by comparing the test–retest results ($\rho = 0.889$ for the NRS, $\rho = 0.671$ for the PGA and $\rho = 0.797$ for the SLAQ score). Agreement was also good with $\rho_c = 0.872$ for the NRS, $\rho_c = 0.659$ for the PGA and $\rho_c = 0.721$ for the SLAQ score.

Correlation with demographic and clinical variables are reported in Table 3. The SLAQ score and PGA both correlated with age at study enrolment ($p = 0.004$ and 0.03, respectively) while NRS did not; no correlation was observed between any component of the SLAQit and disease duration. When compared with physician-driven disease activity scores, NRS and PGA showed a strong positive correlation with both the SLEDAI ($p = 0.002$ and $p < 0.001$, respectively) and ECLAM scores ($p = 0.01$ and $p < 0.001$, respectively), while the SLAQ score did not correlate with SLEDAI or with ECLAM scores. Similar results were obtained by considering the SLEDAI score without the laboratory variables (SLEDAI-nolab). Higher SLAQit scores (both the SLAQ score and the PGA and NRS) were associated with higher daily doses of GC.

Patients in the 75% quartile for all three components of the SLAQit were more likely to be active in accordance with the physician-driven disease

Table 1 Demographic and clinical data of the pilot sample and of the whole cohort

	Pilot sample (N = *35*)	*Whole cohort* (N = *135*)	p
Female *n* (%)	33 (94.3)	124 (91.8)	n.s.
Caucasian *n* (%)	34 (97.1)	131 (97.8)	n.s.
Age (mean ± SD)	43.6 ± 12.5	43.3 ± 12.2	n.s.
Disease duration (mean ± SD)	15.4 ± 10.2	14.3 ± 9.6	n.s.
Kidney cumulative *n* (%)	13 (37)	52 (40)	n.s.
Cutaneous cumulative *n* (%)	18 (51.4)	73 (56.1)	n.s.
Joint cumulative *n* (%)	22 (62.8)	86 (66.1)	n.s.
Serositis cumulative *n* (%)	9 (25.7)	31 (23.8)	n.s.
Hematological cumulative *n* (%)	17 (48.6)	63 (48.5)	n.s.
NPSLE *n* (%)	6 (17.1)	20 (15.3)	n.s.
SLEDAI at enrollment (median, IQR)	2 (0–4)	2 (0–4)	n.s.
ECLAM at enrollment (median, IQR)	1 (0–4)	1 (0–2)	n.s.
SLICC/ACR DI > 0 *n* (%) (Median-IQR)	19 (54.3) 1 (1–3)	72 (53.3) 1 (1–3)	n.s.
Active kidney *n* (%)	3 (8.5)	12 (8)	n.s.
Active cutaneous *n* (%)	4 (11.4)	18 (12)	n.s.
Active joint *n* (%)	6 (17.1)	22 (15)	n.s.
Active hematological *n* (%)	3 (8.5)	11 (7.3)	n.s.
Active NPSLE *n* (%)	0	4 (2.6)	n.s.
Active serositis *n* (%)	0	0	n.s.

NPSLE: neuropsychiatric systemic lupus erythematosus; SLEDAI: Systemic Lupus Disease Activity Index; ECLAM: European Consensus Lupus Activity Measurement; SLICC/ACR DI: Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; IQR: interquartile range; n.s.: not significant; NPSLE: neuropsychiatric systemic lupus erythematosus.

Table 2 Pilot testing and questionnaire responses in the whole cohort

	Pilot test (N = *35*)	*Whole cohort* (N = *135*)	p
Response rate %	99.9		
Time to complete (mean ± SD)	4.6 ± 2.3 min		
SLAQ score (median ± IQR)	10 ± 4–18	11 ± 5–18	n.s.
NRS (median ± IQR)	2.8 ± 1–5	3 ± 1–6	n.s.
PGA (median ± IQR)	0 ± 0–1	0 ± 0–1	n.s.

SD: standard deviation; IQR: interquartile range; n.s.: not significant; SLAQ: Systemic Lupus Erythematosus Activity Questionnaire; NRS: numerical rating scale; PGA: patient global assessment.

activity scores and to take higher daily GC dosage, while no difference in age, disease duration and organ damage was observed (Table 4).

Interestingly, the physician's intention to change therapy was associated with significantly higher NRS (4.8 ± 0.8 vs 3.2 ± 0.26; $p = 0.04$) and PGA scores (1 ± 0.25 vs 0.47 ± 0.7; $p = 0.02$), while no significant association was reported with the SLAQ score ($p =$ n.s.).

Also interesting was that the SLAQ score was strongly associated with the SLICC/ACR DI ($p = 0.005$) while only a mild correlation was observed with NRS ($p = 0.04$) and no correlation with the PGA ($p =$ n.s.).

Discussion

Our study aimed to evaluate reliability, feasibility, acceptability and validity of the Italian version of the self-administered SLAQ (SLAQit). The questionnaire was developed and initially validated in the United States; its validity was subsequently confirmed in the German, Japanese and Swedish versions.[11–13]

After a careful process of translation and transcultural adaptation, the final version of the SLAQit was preliminary tested in a sample of 35 patients and it showed very good feasibility in routine clinical practice as it required less than 10 minutes to be completed by all patients, with a mean time required of less than 5 minutes. All patients filled in the questionnaire in the waiting room, just before attending the visit; all the patients declared that they understood the scope of the questionnaire and only mild (in only one or two questions) content comprehension problems were reported in a minority of patients.

Patients were recruited from the outpatient clinic of our unit; as expected, the overall disease activity was low and only few disease flares were captured from this consecutive recruitment; in addition, as expected, the results of the SLAQit for all three components were skewed toward low scores.

Internal consistency among the SLAQ score, NRS and PGA was good, and the test–retest reliability also showed excellent results. In some cases, however, we observed that patients recorded some symptoms in the SLAQ score while declaring very low global scores for ongoing activity or presence of flares in the previous 3 months (PGA and NRS).

While NRS and PGA showed a moderate correlation with the physician's instruments for disease activity (SLEDAI and ECLAM), the SLAQ score did not, even after removing the laboratory variables from the score (SLEDAI-nolab). As additional support to this correlation, we have observed that patients who reported higher PGA and NRS scores were more likely to be considered active by the treating physician, who intensified the pharmacological treatment; on the other hand, higher SLAQ scores were not always associated with treatment changes. These results could suggest that there is a significant concordance on the general judgment of the disease activity between patients and physicians; however, when a list of symptoms and signs is provided, patients tend to deviate from the physician's judgement by attributing symptoms to disease activity rather than to other causes such as organ damage, comorbidities or adverse events.

These results are in contrast with the German and the Swedish validation study; in fact, Chehab et al. showed a very good correlation between the SLAQ score and the SLAM index, which was the original basis for the SLAQ development. Similarly, Pettersson et al. recently confirmed a good agreement between the Swedish version of the SLAQ and the SLAM scores.[11,13]

One possible explanation of our results might be that we used other disease activity scores as comparator (namely ECLAM and SLEDAI) that cannot allow a direct comparison with the SLAQ score results. Discrepancies in disease assessment between SLAQ and SLEDAI have been reported by others.[12,14] Indeed, despite significant overlapping between SLEDAI descriptors and SLAQ questions, the two instruments demonstrated low agreement when tested simultaneously.[12,14] Moreover, another explanation can rely on the fact that the timeframe for patient symptom recall varies significantly between the SLEDAI (that takes into account the previous 10 days) and the SLAQ (that covers a 3-month period).

Interestingly, in our cohort, the SLAQit was associated with the presence of organ damage and higher GC dosage; while disease duration does not seem to have any influence on the score. This is in contrast to what was recently reported by Pettersson et al., who showed that patients' and physicians' assessments were more discordant for subjects with shorter disease durations.[12] With respect to the Scandinavian cohort, our sample was mainly composed of patients with long disease duration. This could justify the different result and

Table 3 Correlations between SLAQit responses and demographic and clinical variables

	SLAQ score	*NRS*	*PGA*
Age	$r=0.2$, $\mathbf{p=0.004}$	$r=0.12$, $p=$n.s.	$r=$-0.18, $\mathbf{p=0.03}$
Disease duration	$r=0.11$, $p=$n.s.	$r=0.001$, $p=$n.s.	$r=$-0.13, $p=$n.s.
SLEDAI	$r=0.13$, $p=$n.s.	$r=0.26$, $\mathbf{p=0.002}$	$r=0.4$, $\mathbf{p\leq 0.001}$
ECLAM	$r=0.09$, $p=$n.s.	$r=0.21$, $\mathbf{p=0.01}$	$r=0.29$, $\mathbf{p=0.001}$
SLEDAI-nolab	$r=0.12$, $p=$n.s.	$r=0.22$, $\mathbf{p=0.01}$	$r=0.29$, $\mathbf{p<0.001}$
SLICC/ACR DI	$r=0.24$, $\mathbf{p=0.005}$	$r=0.18$, $\mathbf{p=0.04}$	$r=0.11$, $p=$n.s.
GC daily dose	$r=0.36$, $\mathbf{p<0.001}$	$r=0.28$, $\mathbf{p<0.001}$	$r=0.3$, $\mathbf{p<0.001}$

SLEDAI-nolab: Systemic lupus Disease Activity Index without the laboratory variables; ECLAM: European Consensus Lupus Measurement; SLICC/ACR DI: Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; GC: glucocorticoids; n.s.: not significant. Statistically significant correlations are in bold.

Table 4 Characteristics of patients with higher scores versus lower scores

	Patients with scores above 75% (N = 17)	*Patients with score below 75% (N = 118)*	p
Age (years) (mean ± SD)	43 ± 3.3	42 ± 1.0	n.s.
Disease duration (years) (mean ± SD)	14.5 ± 2.8	15.3 ± 0.8	n.s.
SLEDAI (mean ± SD)	5.3 ± 1.2	2.4 ± 0.23	**0.002**
ECLAM (mean ± SD)	2.0 ± 0.1	1.1 ± 0.4	**0.01**
GC daily dose (mean ± SD)	4.3 ± 1	2.2 ± 0.3	**0.02**
SLICC/ACR DI (mean ± SD)	1.6 ± 0.5	1 ± 0.1	n.s.

SD: standard deviation; SLEDAI: Systemic lupus Disease Activity Index; ECLAM: European Consensus Lupus Measurement; GC: glucocorticoids; SLICC/ACR DI: Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; n.s.: not significant. Statistically significant correlations are in bold.

could support the idea that patients tend to confuse features of organ damage with disease activity.

In our opinion, these data raise two crucial issues to be considered. First, physician-rated and patient-reported evaluations can have different results; in detail, more disease activity was recounted with the SLAQ suggesting that its subjective nature might lead to an over-reporting of symptoms (mainly due to chronic damage) that the patient attributes to disease activity; this aspect can be responsible for patient disappointment, drug failure, poor adherence to physician's recommendations and poor outcomes. To overcome this problem, more effort should be made in patient education, patient participation in disease management and, in the end, in patient empowerment.

Second, these results can also serve as a reminder that in SLE there is a significant gap between the patient's and the physician's view of the disease. Indeed, it is well known that while patients tend to focus on self-perceived functions, physicians tend to be more concerned with clinical signs and laboratory features.[2,15] Interestingly, in an Australian survey of 386 patients with SLE, tiredness (81%), pain (73%), not being able to do the things one used to (72%), fear of exacerbation (72%), sleep problems (70%), anxiety/stress (69%) and feeling down/depressed (68%) were all rated highly as unmet needs in the actual SLE management.[16] These findings suggest that patients' physical, psychological and practical concerns are not being managed adequately, possibly causing interruptions in treatment and misunderstandings in communication between patients and treating physicians. On the other hand, it is increasingly evident that the ways to improve outcomes in SLE patients could benefit from patient-oriented research focusing on the multifaceted dimensions of the disease burden.

Considering these data, it is clear that these kinds of instruments are very important as a means to analyze the different perspectives and the communication gap between patient and doctor. Thus, SLAQit would not substitute for the physician-driven disease activity scores, but it would integrate the disease activity evaluation with the patient's point of view, by capturing those symptoms that have most impact on patient's life.

With this purpose, the SLAQit could be used as a screening instrument that the patient might complete in the waiting room before the routine visit; the physician could then evaluate the results, enabling them to have a quick view of the patient's perception of disease activity during the previous months.

In conclusion, the SLAQit questionnaire appears to be feasible and reliable in routine clinical care and it can be a valid help for the treating physician to screen for the presence of self-reported symptoms that should be further investigated during the visit. It is not to be used *instead of* a physician-driven disease assessment but *in addition to it*, in order to have a more complete disease evaluation that includes the patient's perspective.

Additional studies are needed to understand the role of this index in routine clinical practice and also its impact on outcomes in clinical trials; it can be also a useful tool to engage and empower patients in the management of their disease.

Declaration of conflicting interests

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