Reumatol Clin. 18 (2022) 355–360

Sociedad Española de Reumatología - Colegio Mexicano de Reumatología

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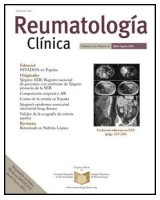

Original Article

Validation of the LupusQoL in Venezuela: A specific measurement of quality of life in patients with systemic lupus erythematosus☆

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ARTICLE INFO

Article history:
Received 13 October 2020
Accepted 14 February 2021
Available online 7 August 2021

Keywords:
Systemic lupus erythematosus
Quality of life
Surveys and questionnaires
Venezuela

ABSTRACT

Background and objectives: Traditionally, the health-related quality of life (HRQoL) of patients with systemic lupus erythematosus (SLE) has been assessed using instruments that neglect the specific characteristics of the disease. This study determines the validity of the Lupus Quality of Life (LupusQoL) questionnaire as a psychometrically stable instrument to measure the HRQoL of patients with SLE in Venezuela and establishes the cutoff points of the questionnaire for the Venezuelan population.
Patients and methods: A cross-sectional study was conducted that included patients with SLE from April to July 2018. Patients completed the LupusQoL and the "*Generalitat de Catalunya*" (GENCAT) scale; sociodemographic data, activity index (SLEDAI) and accumulated damage (SLICC), were obtained. Reliability was evaluated by internal consistency and the convergent validity of the LupusQoL was determined with the GENCAT scale.
Results: Of the 100 patients, 93% were women, the mean age was 42 years old (SD: 13) and the mean duration of the disease was 11 years (SD: 9); the mean of SLEDAI and SLICC was 3 and 1, respectively. The cutoff point that defined a "better" or "worse" HRQoL for LupusQoL was 64.55 points. A moderate convergence was found after grouping, according to the cutoff points, of the LupusQoL with the GENCAT scale (Cohen's kappa coefficient = .556; p = .000).
Conclusions: The LupusQoL is a valid psychometrically stable instrument to measure the HRQoL of patients with SLE in Venezuela. Cutoff points were established to stratify the HRQoL in the Venezuelan population with LES, being useful to complement a comprehensive evaluation.

Validación del LupusQoL en Venezuela: una medida específica de la calidad de vida en pacientes con lupus eritematoso sistémico

Palabras clave:
Lupus eritematoso sistémico
Calidad de vida relacionada con la salud
Encuestas y cuestionarios
Venezuela

RESUMEN

Antecedentes y objetivos: Tradicionalmente, la calidad de vida relacionada con la salud (CVRS) de los pacientes con lupus eritematoso sistémico (LES) ha sido evaluada utilizando instrumentos que desatienden las características específicas de la enfermedad. Este estudio determina la validez del cuestionario Lupus *Quality of Life* (LupusQoL) como instrumento psicométricamente estable para medir la CVRS de los pacientes con LES en Venezuela, y establece los puntos de corte del cuestionario para la población venezolana.

☆ Please cite this article as: Carrión-Nessi FS, Marcano-Rojas MV, Freitas-DeNobrega DC, Romero Arocha SR, Antuarez-Magallanes AW, Fuentes-Silva YJ. Validación del LupusQoL en Venezuela: una medida específica de la calidad de vida en pacientes con lupus eritematoso sistémico. Reumatol Clin. 2022;18:355–360.

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Pacientes y métodos: Se realizó un estudio de corte transversal que incluyó pacientes con LES desde abril hasta julio de 2018. Los pacientes completaron el LupusQoL y la escala *Generalitat de Catalunya* (GENCAT); se obtuvieron los datos sociodemográficos, índices de actividad (SLEDAI) y daño acumulado (SLICC). Se evaluó la fiabilidad mediante consistencia interna y se determinó la validez convergente del LupusQoL con la escala GENCAT.
Resultados: De los 100 pacientes, el 93% eran mujeres, la media de edad fue de 42 años (DE: 13) y la media de duración de la enfermedad fue de 11 años (DE: 9); la media de SLEDAI y SLICC fue de 3 y 1, respectivamente. El punto de corte que definió una «mejor» o «peor» CVRS para el LupusQoL fue 64,55 puntos. Se encontró una convergencia moderada posterior a la agrupación, según los puntos de corte, del LupusQoL con la escala GENCAT (coeficiente kappa de Cohen = 0,556; p = 0,000).
Conclusiones: El LupusQoL es válido como instrumento psicométricamente estable para medir la CVRS de los pacientes con LES en Venezuela. Se establecieron los puntos de corte que permiten estratificar la CVRS de los pacientes venezolanos con LES, siendo de utilidad para complementar una evaluación integral.

Introduction

Systemic lupus erythematosus (SLE) is chronic, autoimmune disease of unknown aetiology with variable clinical presentation and severity. It presents with a relapsing and remitting pattern of progression which is characterised by periods of remission and activity[1]. Life expectancy of patients with SLE has improved due to early diagnosis and better therapeutic strategies. However, the use of drugs which are not toxicity-free, together with the actual symptoms of the disease, significantly impact the quality of life of these patients[2]. Health-related quality of life (HRQoL) must be considered both in the right treatment and control of the disease as well as in patients' evolution with SLE[3].

Different studies report that there is poorer HRQoL in patients with SLE compared with healthy people and similar HRQoL—or at times worse—compared with other chronic patients[4–7]. According to Testa[8], measuring HRQoL provides a description of a health condition or status, pointing out changes on how the patient functions, providing a prognosis or establishing reference guidelines. The HRQoL of patients with SLE has been assessed using two types of tools[9]: generic questionnaires, such as the Medical Outcome Survey Short Form 36 (MOSSF-36) and the European Quality of Life Questionnaire-5 Dimensions (EQ-5D), which lack specific domains for SLE; and specific questionnaires such as the Systemic Lupus Erythematosus Quality of Life Questionnaire (SLEQOL), the Systemic Lupus Erythematosus Symptom Checklist (SSC), the Systemic Lupus Erythematosus Quality of Life Scale (L-QoL) and the Lupus Quality of Life (LupusQoL).

The LupusQoL was validated using several cross-sectional and longitudinal studies in patients with SLE[2,10–19]. However, there are no published data to determine the validity of the questionnaire nor cut-off values to stratify HRQoL in Venezuelan patients with SLE. As a result and given the importance of measuring quality of life in these patients, the aims of this study were to determine the validity of the LupusQoL as a psychometrically stable tool for measuring HRQoL in Venezuelan patients with SLE and establishing cut-off points of the questionnaire for the Venezuelan population. We chose this specific tool because its items are based on the perception of the HRQoL of the patients themselves who have SLE. A score is given by domains with the higher sensitivity, specificity, and response capability (sensitivity to change) than the generic questionnaires and their development and validation prove they have stable psychometric properties[10,20]. Standardisation of this technique will allow researchers and healthcare providers to objectively analyse the HRQoL of Venezuelan patients with SLE and to use this information to improve the quality of medical care for these patients. In addition to this, this method may be adopted by other countries of the Americas with similar patient populations.

Materials and methods

Patients and study design

A cross-sectional study was conducted that included patients with SLE who were attached to the External Consultation centre of the Rheumatology Unit of the "Ruíz y Páez" University Hospital Complex and the Centro Clínico Universitario de Oriente in Ciudad Bolívar, Venezuela, between April and July 2018, with at least 4 classification criteria from the 1982 American College of Rheumatology[21]. Patients with additional diagnoses of other different autoimmune diseases to SLE were excluded, save those patients with a diagnosis of anti-phospholipid syndrome.

Ethical aspects and informed consent

The study was conducted in keeping with the ethical principles for medical research in human beings from the Declaration of Helsinki[22], with the corresponding informed consent signed by all patients.

Tools

The LupusQoL[10] questionnaire, consolidated with a valid, reliable HRQoL from the patient and specific to the disease for adults with a diagnosis of SLE, contains eight domains and a total of 34 items which are responded to using a five-point Likert scale. It gives a score by domains which ranges from 0 (worse HRQoL) to 100 (best HRQoL), which may be obtained if the following formula is followed: the responses by domain are added up and divided by the total number of items of this domain. The resulting score is divided by 4 and then multiplied by 100.The version translated into Spanish of the LupusQoL was used; usage licence was requested through the online system of RWS Life Sciences, Inc.

The "*Generalitat de Catalunya*"[23] (GENCAT) scale form — an objective tool designed in keeping with advances made on the multidimensional general quality of life model proposed by Schalock in 2002 and Verdugo in 2003 was used. It contains eight dimensions and a total of 69 items which are responded to using a four-option scale of frequency. The GENCAT scale is a valid and reliable tool[23] which has been used in national[24,25] and international studies[26,27] to measure the quality of life in patients with SLE.

The accumulated disease activity and damage were calculated through the Systemic Lupus Erythematosus Disease Activity Index[28] (SLEDAI) and Systemic Lupus International Collaborating Clinics[29] (SLICC), respectively. The SLEDAI assesses disease activity in the last 10 days and includes 24 items which determine specific symptoms in 9 organs or systems, with a maximum score of 105[28]. The SLICC assesses irreversible damage of the disease during the last

6 months and includes 42 items to measure involvement of the 12 domains with a maximum score of 46 points[29]. Both models have been proven to be valid and reliable for assessing activity (SLEDAI) and accumulated damage (SLICC) in patients with SLE[28,29].

Procedure

Patients were approached during their routine rheumatology consultation. Those who agreed to participate in the study received an envelope with an informed consent form, a sociodemographic data form, a copy of the LupusQoL and a copy of the GENCAT scale for them to complete in the medical centre or take home to complete and deliver within a week. The patients who could not read or write received help to complete the documents, with by the authors in the medical centre or their family members when they were at home.

The SLEDAI and SLICC indices of the medical records for the previous 6 months were later obtained.

Statistical analysis

Reliability was determined by internal consistency using Cronbach's alpha coefficient. Cut-off points were generated for the LupusQoL and the GENCAT scale from an analysis of latent classes which highlighted one or more non observed (latent) classes with respect to a variable. By applying an analysis of the Bayesian information criterion values, we confirmed that two classes were optimum for both questionnaires. Means and marginal probabilities were then studied for the latent classes, grouping each patient into one of the two classes. From these, using Receiver Operating Characteristics curves (ROC), the cut-off points for the LupusQoL were determined (for each domain and the total) and for the GENCAT scale. These cut-off points led to stratifying the HRQoL of the patients into "better" or "worse". Convergent and discriminating validity was analysed using Cohen's kappa coefficient and the Spearman correlation coefficient, respectively. Finally, the predictive validity was analysed using COR curves with SLEDAI and SLICC values grouped into: <4 or ≥4 points and 0 or ≥1 point, respectively; these cut-off points were taken because they had been satisfactorily used in previous validation studies of LupusQoL[11–16,19]. The STATA version 16 and the SPSS version 25 were used for statistical analysis. Statistical significance was set at $p < .05$.

Results

Sociodemographic characteristics

A total of 100 patients with SLE completed the questionnaires; 93% were women, with mean age at 42 years (SD: 13) and mean disease duration of 11 years (SD: 9). SLEDAI and SLICC means were 3 and 1, respectively. The other sociodemographic characteristics are contained in Table 1.

Reliability

Internal consistency was .96, which proves LupusQoL's high reliability.

Cut-off points

The highest correctly classified patient percentage (99%) was obtained with a value of 64.55 points in the LupusQoL (area below the curve = .99; sensitivity: 100%; specificity: 97.56%), suggesting that the patients with 64.55 points or more presented with a good HRQOL (Fig. 1). Furthermore, cut-off points for each LupusQoL domain (Table 2) domain were obtained.

Table 1
Sociodemographic characteristics of Venezuelan patients with SLE.

n = 100	
Female sex, n (%)	93 (93)
Mean age, years (SD)	42 (13)
Level of education, n (%)	
Illiterate	4 (4)
Primary level	13 (13)
Secondary level	40 (40)
Further education level	43 (43)
Mean study time, years (SD)	12 (4)
Mean disease duration, years (SD)	11 (9)
SLEDAI, mean (SD)	3 (4,7)
SLICC, mean (SD)	1 (1)

SD: standard deviation.

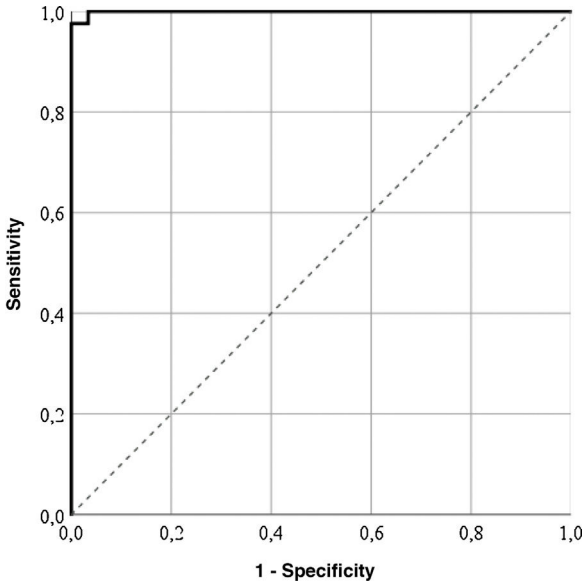

Fig. 1. ROC curve of the LupusQoL in Venezuelan patients with SLE.

Convergent validity

For the GENCAT scale, the cut-off points which correctly classified most patients (95%) was 67 points (area under the curve = .98; sensitivity: 92.73%; specificity: 97.78%), and patients with the same or higher score to this sum therefore presented with a better quality of life (Fig. 2). After grouping the patient in accordance with the LupusQoL cut-off points and the GENCAT scale, a moderate convergent validity which was statistically significant was obtained (Cohen's kappa coefficient = .556; p = .000).

Discriminant validity

The LupusQoL was inversely correlated with the SLEDAI (rho = –3.27; p = .001) (Fig. 3A) and with the SLICC (rho = –.246; p = .014) (Fig. 3B) significantly.

Predictive validity

The LupusQoL discreetly predicted disease activity (SLEDAI) for scores ≥4 (area under the curve = .704; sensitivity: 74.24%; specificity: 67.65%) (Fig. 4A), classifying 72% of patients. The LupusQoL gave a poor prediction of accumulated damage (SLICC) for scores

Table 2
Cut-off points of the LupusQoL in Venezuelan patients with SLE.

Domains	Scoring of the cut-off points	Area under the curve	p	Correctly classified patients (%)	Sensitivity (%)	Specificity (%)
Physical health	56.25	.993	0	97	100	89.6
Pain	58.33	1	0	100	100	100
Planning	66.66	1	0	100	100	100
Sexual relations	65.2	1	0	100	100	100
Burden for others	58.33	1	0	100	100	100
Emotional health	54.16	.99	0	99	98.65	100
Body image	70	.99	0	98	97.3	100
Fatigue	56.35	.99	0	98	100	95.24
Total	64.55	.99	0	99	100	97.56

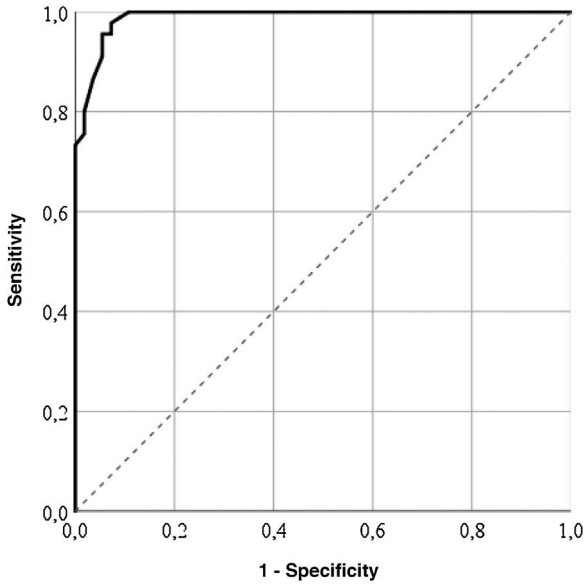

Fig. 2. ROC curve of the GENCAT scale in Venezuelan patients with SLE.

≥1 (area under the curve = .642; sensitivity: 66.67%; specificity: 52.94%) (Fig. 4B), classifying only 62% of patients.

Average scores for each domain of the LupusQoL were compared in patients with and without disease activity (SLEDAI: <4 or ≥4 points), and also in patients with or without accumulated damage (SLICC: 0 or ≥1 points) (Table 3), with significant differences being found between both groups in all domains, except in "sexual relations" for the SLEDAI and SLICC scales and "burden for others" for the SLICC scale.

Discussion

During the last decade, assessing the HRQoL of patients with SLE has attracted major interest[11]. This study determines the valid-

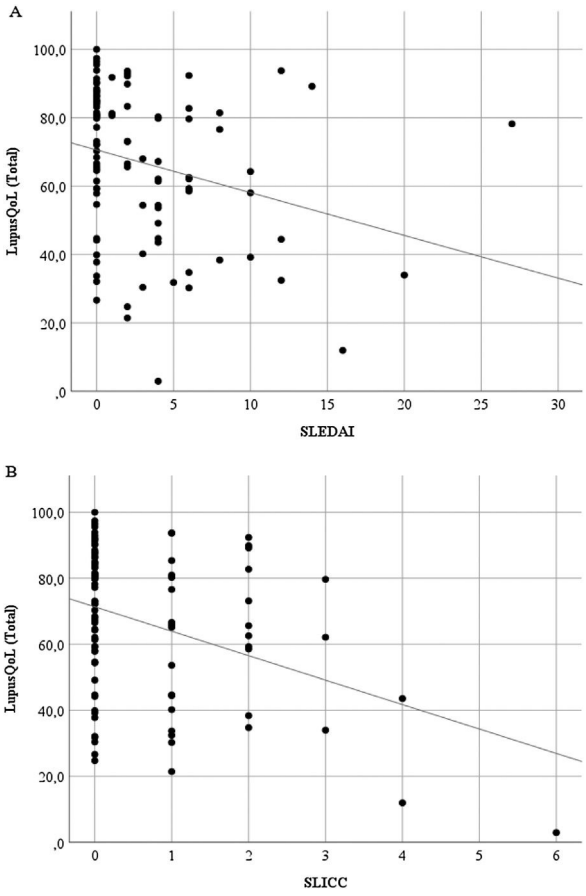

Fig. 3. Correlation between the SLEDAI and the SLICC with LupusQoL in Venezuelan patients with SLE. (A) Correlation between the SLEDAI and the LupusQoL. (B) Correlation between the SLICC and the LupusQoL.

Table 3
Scoring of the LupusQoL according to the disease activity (SLEDAI) and the accumulated damage (SLICC) in Venezuelan patients with SLE.

Domains	SLEDAI		p[a]	SLICC		p[a]
	<4 n = 66	≥4 n = 34		0 n = 66	≥1 n = 34	
Physical health	72.1 (24.0)	58.2 (25.8)	.009	73.1 (21.1)	56.3 (29.4)	.001
Pain	67.2 (27.2)	49.8 (25.4)	.003	67.0 (25.2)	50.0 (29.4)	.003
Planning	78.8 (26.4)	65.0 (27.1)	.016	78.8 (24.6)	65.0 (30.4)	.016
Sexual relations	72.3 (29.4)	65.1 (32.2)	.259	71.2 (28.6)	67.3 (34.0)	.543
Burden for others	64.5 (30.1)	46.3 (35.0)	.008	61.4 (31.2)	52.5 (35.5)	.2
Emotional health	72.3 (24.7)	53.9 (27.6)	.001	71.3 (24.4)	55.8 (29.2)	.006
Body image	82.3 (22.8)	66.2 (23.1)	.001	80.2 (23.4)	70.4 (24.4)	.056
Fatigue	64.96 (23.43)	50.92 (26.16)	.008	64.96 (22.22)	50.92 (28.17)	.008
Total	71.81 (20.42)	56.91 (22.51)	.001	70.99 (19.62)	58.51 (24.81)	.007

[a] Student's t-test. Data are presented as mean and standard deviation.

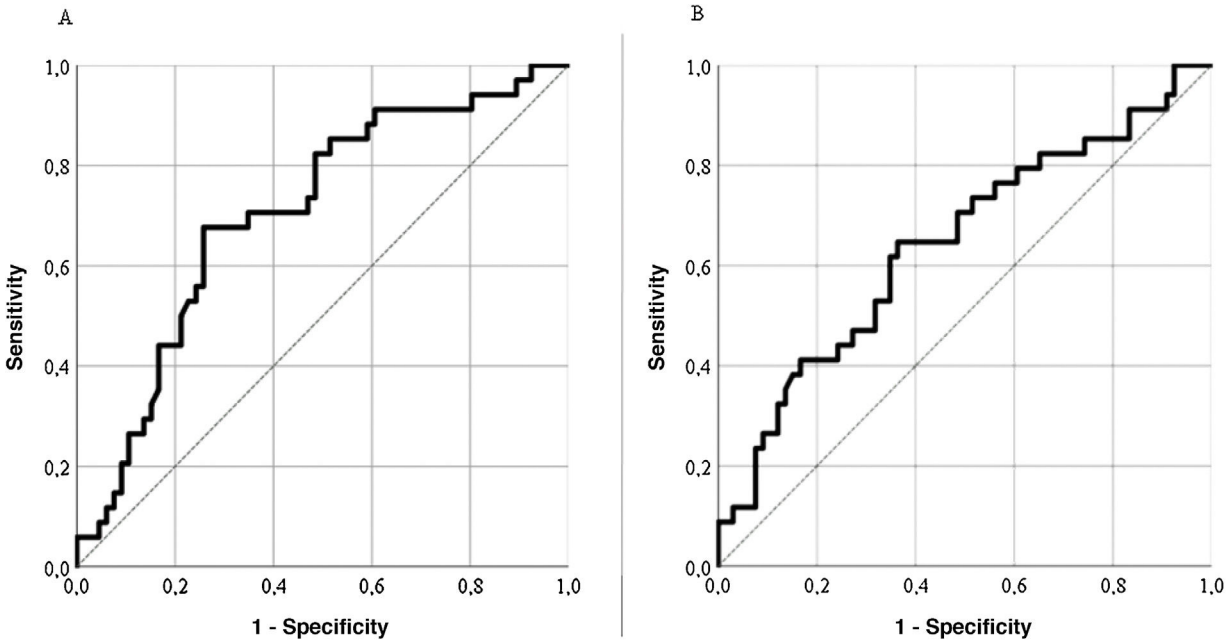

Fig. 4. ROC curves of the LupusQoL with the SLEDAI and the SLICC in Venezuelan patients with SLE. (A) ROC curves of LupusQoL with the SLEDAI. (B) ROC curves of the LupusQoL with the SLICC.

ity of a specific tool for measuring the HRQoL of patients with SLE (LupusQoL) and is the first to establish cut-off points that stratify the HRQoL of these patients in Venezuela. The HRQoL of the patients with SLE must consider both the generic domains (physical, emotional and social well-being) and specific domains (pain, sexual relationships, body image, among others) affected by the disease[30]; this ensures that the results of the domains assessed by a tool will be objective measures of the HRQoL.

In this study, analysis of Cronbach's alpha coefficient (.96) demonstrated the high reliability of the LupusQoL, in keeping with studies conducted in Latin America[11,30], the United States[12], Europe[2,10,13–15] and Asia[16,17]. A moderate convergence was also found between the LupusQoL and the GENCAT scale, similar to that reported by several studies[2,10–17] which obtained good consistency between the equivalent domains of the LupusQoL and other generic scales. It is well known that the generic questionnaires present a modest convergence with the specific questionnaires, although they measure different parameters of the HRQOL[11].

It was also determined that the LupusQoL slightly discriminates the activity of the disease measured by the SLEDAI and the accumulated damage measured by the SLICC in patients with SLE. Current reports on the ability of the LupusQoL to discriminate disease activity and accumulated damage are variables. Several studies show that the LupusQoL does not discriminate between disease activity[11,31,32] or accumulated damage[11] but most studies present the results for each domain of the questionnaire because there was no equivalence between them and they did not present with significant differences in all domains[2,10,12–14,16,17]. These discrepancies may be due to many causes, including sociodemographic differences and relationships with the disease among different population groups.

The predictive value of the LupusQoL shows that this questionnaire is useful for predicting disease activity and accumulated damage, since statistically significant differences were found between both groups in all domains, except in "sexual relations" for SLEDAI and SLICC and in "burden for others" for SLICC. This contrasts with what was found by Machado et al.[11] who reported that the score of the LupusQoL was inappropriate for predicting disease activity and accumulated damage. Furthermore, no significant differences were reported among scores for each domain of LupusQoL according to the "best" or "worst" HRQoL. Research on these findings needs to be extended in the future for a better analysis.

This study has several limitations: first, 20% of the SLEDAI indices were obtained from a variable point of one to six months between the day of the application of the tools and the most recent indices. Second, the reproducibility of the LupusQoL was not measured through the test-retest.

To conclude, the LupusQoL is valid as a psychometrically stable tool for measuring the HRQoL of Venezuelan patients with SLE. The cut-off points that enable stratification of the HRQoL of the Venezuelan patients with SLE were established and were highly useful for completely assessing the disease progression in these patients and their prognosis.

Financing

This research study did not receive any specific funding from public sector, commercial sector or not-for-profit entities.

Conflict of interests

The authors have no conflict of interests to declare.

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