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Self-reported disease severity in women with systemic lupus erythematosus

A. Dima[1,2] · S. Caraiola[1,2] · C. Delcea[1,2] · R. A. Ionescu[1,2] · C. Jurcut[3] · C. Badea[1,2]

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Abstract

Systemic lupus erythematosus (SLE), pathology with net feminine predominance, is one of the most complex autoimmune diseases and has major impact on patients' life. The aim is to identify patient and disease-related factors associated with self-perceived disease severity in female SLE patients. This cross-sectional study enrolled 73 women fulfilling the 2012 Systemic Lupus International Collaborating Clinic (SLICC) criteria. SLE disease activity was assessed by the Systemic Lupus Activity Measure (SLAM) score and overall damage by the SLICC/American College of Rheumatology (ACR) index. Patients' general characteristics, associated conditions as well as SLE specific clinical involvements and therapeutic principles were also noted. Fatigue was assessed by FACIT-fatigue scale. Self-perceived disease severity was assessed using numerical rating scales (1–10 NRSs), to evaluate the disease severity at inclusion (1–10 NRS now) and worst severity anytime during disease history (1–10 NRS worst ever). In regard to worst ever lupus severity, 54.8% of patients responded with 9 or 10, while none with 1 or 2 even if only 22.9% of the patients responded with 7 or more for disease severity at inclusion (1–10 NRS now). Women with higher 1–10 NRS now answers had also higher 1–10 NRS worst ever, SLAM, SLICC, and FACIT-fatigue scores. They associated more frequently anxiety/depression diagnosis, antiphospholipid syndrome, joint involvement as well as treatments with corticosteroids. Self-reported disease severity worst ever, anxiety/depression diagnosis, fatigue, and the daily dose of corticosteroids were independently associated with patients' perception on lupus severity at inclusion: OR (95% CI), 2.13 (1.15–3.94) $p=0.017$, 6.67 (1.11–39.97) $p=0.038$, 1.10 (1.02–1.19) $p=0.018$, and 1.11 (1.02–1.21) $p=0.020$, respectively. The vast majority of patients identified severe and very severe events during their disease history, results that raise awareness of burden concerning lupus occurrence in women's life. Self-perceived lupus severity is multifactorial, influenced also by factors less considered in the SLE management like fatigue and the depression/anxiety disorders, but also by the previous patient's experience.

Keywords Systemic lupus erythematosus · Fatigue · Women's health · Self-rated health · Disease activity

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✉ A. Dima
alina_dima@outlook.com

S. Caraiola
scaraiola@yahoo.com

C. Delcea
caterina.delcea@gmail.com

R. A. Ionescu
tane67@gmail.com

C. Jurcut
cjurcut@gmail.com

C. Badea
cameliabadea72@yahoo.com

[1] Internal Medicine Department, Carol Davila UMF, Dionisie Lupu Street 37 020022 Bucharest S2, Romania

[2] Internal Medicine Department, Colentina Clinical Hospital, Bucharest, Romania

[3] Dr Carol Davila Central University Emergency Military Hospital, Bucharest, Romania

Introduction

Systemic lupus erythematous (SLE) is one of the most heterogeneous autoimmune diseases in regard to clinical and immunological criteria, that affects many organs, has net feminine occurrence, but incidence that varies in different populations [1]. Furthermore, the humanistic burden is high in lupus, influenced by numerous symptoms of the disease itself, treatment adverse effects, or related comorbidities [2].

SLE has negative impact on patients' well-being, affecting all facets of health-related quality of life [3]. The ability to perform daily activities is impaired [4] in as much as two-thirds of the SLE population [5]. However, the patient-reported tools analyzing the disease impact on patients' well-being do not necessarily correlate with the physicians' assessment [6–8]. Therefore, understanding of SLE impact should integrate the patient's own perception over symptomatology, chronic or flares [9, 10]. Patients' beliefs might be linked to disease impact and adherence to treatment [11] and better understanding of the patients' view and unmet needs could improve their compliance and satisfaction [12].

Numerical Rating Scale (NRS), Verbal Rating Scale, or Visual Analogue Scale (VAS) was developed and used initially for the pain intensity assessment [13, 14] and due to their usefulness were then adopted with other indications also. Moreover, patient-reported measures, especially VASs, are also frequently used in rheumatologic and immune diseases especially for the patients' assessment in clinical trials.

The objective of this study was to identify the patient and disease-related determinants of self-reported lupus severity as assessed by NRS ranging from 1 to 10 (1–10 NRS), evaluating the worst severity perceived anytime during disease history (1–10 NRS worst ever) and the disease severity at inclusion (1–10 NRS now).

Methods

Study population

A cross-sectional study with inclusion of patients fulfilling the 2012 SLE Systemic Lupus International Collaborating Clinic (SLICC) criteria was conducted [15]. Only female patients were considered for this analysis, given that SLE has net feminine predominance (9:1) and also considering the possible differences in perception between women and men. Oral and written informed consent was obtained in all cases. Hospital's Ethics Committee approved the research (30/19.10.2015).

Measure of disease-related features

Background variables concerning age, disease duration, smoking, and alcohol consumption were collected. SLE disease activity was assessed by the Systemic Lupus Activity Measure (SLAM) [16] and the overall irreversible impairment was estimated by the Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR) Damage Index [17]. We defined lupus specific clinical involvements according to the 2012 SLICC classification criteria after discussion and clinical examination of each patient. The Functional Assessment of Chronic Illness Therapy—Fatigue Scale (FACIT-Fatigue) was used for fatigue assessment (http://www.facit.org) [18]. All scores used were actively completed in the moment of the patients' inclusion for research purposes. Data about disease history and treatment management were collected from patients' interviews and available medical files. Diagnosis of Sjogren's syndrome, antiphospholipid syndrome, and psychiatric diagnosis was established in our clinic by specialist in each field according to the current clinical practice criteria and was appraised for this study from the patients' hospital files.

1–10 Numerical Rating Scale (1–10 NRS)

Patients were asked to choose the appropriate number from 1 to 10 (where 1 meant no activity and 10 was equivalent to maximum disease severity) on two questions (Suppl File). First, 1–10 NRS worst ever: "From 1 to 10, how severe was your illness (lupus) in the worst moment from the diagnosis?". The second one, 1–10 NRS now: "From 1 to 10, how severe is your illness (lupus) in this moment?". Several disease severity levels were arbitrarily defined for this study purpose, according to the numbers selected as follows: 1 or 2 no severity, 3 or 4 mild severity, 5 or 6 moderate severity, 7 or 8 severe disease and 9 or 10 very severe disease.

Statistical analysis

The parametric variables were presented as mean and standard deviation (SD), the non-parametric ones as median (med) with the interquartile range (IQR)-Q25 first quartile, Q75 third quartile, and nominal variables as percentages. As there are no available data in the literature, a hazard cutoff for defining high 1–10 NRS now based on the answers' results distribution, the value of the Q75 (namely, the response 6 out of 10) was used to split the lot into two groups with eligible number of patients for the statistics applied (low vs high self-perceived severity). Since the median of the responses for NRS1-10 now

was lower than 5, we considered inappropriate to use it when defining severe disease. According to the variable's type, a bivariate analysis by Mann–Whitney test or by the Chi-square test was performed to identify the associations of the self-reported disease severity at present with lupus-related features. Parameters associated with a p value < 0.05 in bivariate analysis were then tested in a regression model. Binary logistic regression by enter method with odds ratio (OR) and 95% confidence intervals (CIs) was assessed to identify predictors of high self-perceived disease severity. In all tests, p values less than 0.05 were considered statistically significant. IBM SPSS 16.0 Statistics software was used.

Results

A total of 73 women fulfilling the 2012 SLICC SLE criteria were included. Mean (SD) age at inclusion was 47.4 ± 11.8 years. Sjogren's syndrome and the antiphospholipid syndrome diagnosis were previously established in 14 (19.2%) and 22 (30.1%) patients, respectively. Depression

Table 1 Descriptive data and analysis of the parameters associated with self-perceived disease severity in systemic lupus erythematosus

Characteristic	$N = 73$	1–10 NRS now		
		Low response < 6/10	High response ≥ 6/10	p value
Age, years mean (SD)	47.4 ± 11.8	45.6 ± 12.1	50.8 ± 10.5	0.126
Disease duration, years med (IQR)	9 (4–12.5)	8.5 (4.3–13.5)	9 (4–12.8)	0.731
Smoking, yes/no med (IQR)	10 (13.7)	7 (9.6)	3 (12)	0.603
Alcohol, yes/no med (IQR)	6 (8.2)	4 (8.3)	2 (8)	0.961
1–10 NRS worst ever med (IQR)	9 (7–10)	8 (6.3–10)	10 (8–10)	0.012
SLAM score, points med (IQR)	4 (2–5)	3 (2–5)	6 (4–10)	0.021
SLICC index, points med (IQR)	1 (0–2)	1 (0–2)	1 (1–3)	0.019
FACIT-fatigue scale, points med (IQR)	9 (5–19)	6 (1–14.8)	19 (9.5–25.5)	< 0.001
Anxiety/depression disorder, yes n (%)	21 (28.8)	10 (20.8)	11 (44)	0.038
Sjogren's syndrome, yes n (%)	14 (19.2)	10 (20.8)	4 (16)	0.619
Antiphospholipid syndrome, yes n (%)	22 (30.1)	9 (18.8)	13 (52)	0.012
Raynaud phenomenon, yes n (%)	34 (46.6)	25 (52.1)	9 (36)	0.191
Cutaneous anytime, yes n (%)	49 (67.1)	18 (37.5)	19 (76)	0.244
Ulcers anytime, yes n (%)	31 (42.5)	20 (41.7)	11 (44)	0.848
Alopecia anytime, yes n (%)	41 (56.2)	26 (54.2)	15 (60)	0.634
Joint anytime, yes n (%)	59 (80.8)	35 (72.9)	24 (96)	0.017
Serositis anytime, yes n (%)	24 (32.9)	16 (33.3)	8 (32)	0.908
Renal anytime, yes n (%)	26 (35.6)	15 (31.5)	11 (44)	0.280
Neurologic anytime, yes n (%)	23 (31.5)	12 (25)	11 (44)	0.097
Hematologic anytime, yes n (%)	51 (69.9)	33(68.8)	18 (72)	0.774
Cutaneous in present, yes n (%)	21 (28.8)	13 (27.1)	8 (32)	0.660
Ulcers in present, yes n (%)	8 (11)	6 (12.5)	2 (8)	0.559
Alopecia in present, yes n (%)	22 (30.1)	11 (22.9)	11 (44)	0.062
Joint in present, yes n (%)	19 (26)	10 (20.8)	9 (36)	0.161
Serositis in present, yes n (%)	2 (2.7)	1 (2.1)	1 (4)	0.634
Renal in present, yes n (%)	5 (6.8)	2 (4.2)	3 (12)	0.209
Neurologic in present, yes n (%)	4 (5.5)	1 (2.1)	3 (12)	0.077
Hematologic in present, yes n (%)	26 (35.6)	15 (31.3)	11 (44)	0.280
Hydroxychloroquine, years med (IQR)	6 (1–10)	6.5 (3.3–10)	3 (0.8–10)	0.157
Corticosteroids, years med (IQR)	6 (1.5–11)	6 (2–11)	6 (1–12)	0.884
Hydroxychloroquine in present, yes n (%)	60 (82.2)	41 (85.4)	19 (76)	0.318
Corticosteroids daily dose, mg med (IQR)	10 (5–20)	10 (0–15)	15 (6.3–20)	0.017

IQR interquartile range: Q25 first quartile (25th percentile), Q75 third quartile (75th percentile), p value significant < 0.05. Mann–Whitney test assessed for continuing variable, while the Chi-square test for the nominal variables

1–10 NRS 1 to 10 numerical rating scale, *FACIT* fatigue functional assessment of chronic illness therapy fatigue scale, *SLAM* systemic lupus activity measure, *SLE* systemic lupus erythematosus, *SLICC* systemic lupus international collaborating clinics

and anxiety-related disorders were the only psychiatric diagnoses registered in the patients' files, noted in 28.8% patients. Descriptive data are presented in Table 1.

The 1–10 NRS results were 9 (7–10) for the overall worse severity declared, respectively, 4 (2–6) for disease severity now. 54.8% of patients identified very severe flares during their disease history, while only 4.1% of the patients admitted having a very severe disease at inclusion (Suppl File).

In regard to the objective lupus assessment, the SLAM score result was 4 (2–5) points, while the SLICC index was 1 (0–2) points. Patients with higher self-perceived disease severity had also higher SLAM score and SLICC index results, 6 (4–10) vs 3 (2–5) points, $p = 0.021$ and 1 (1–3) vs 1 (0–2) points, $p = 0.019$, respectively. Moreover, anxiety or depression diagnosis [10 (28%) vs 11 (44%) patients, $p = 0.038$], antiphospholipid syndrome diagnosis [9 (18.8%) vs 13 (52%) patients, $p = 0.012$], or the joint involvement anytime during disease history [35 (72.9%) vs 24 (96%) patients, $p = 0.017$] was more frequent in patients with higher self-reported disease severity at inclusion (Table 1). We did not identify significant differences concerning self-perceived disease activity for other SLE organ involvements.

The patients with more severe self-perceived disease severity were currently treated with higher corticosteroid daily doses. We had insufficient data to perform analysis regarding immunosuppressive or biological therapies. We also did not identify any relation in regard to the Hydroxychloroquine use.

Multivariate logistic regression was performed to evaluate the associations of disease-related parameters with patients' perception of lupus severity. In this analysis, the anxiety and depression occurrence were associated with high self-reported disease severity of 6.67 (95% CI 1.11–39.97), $p = 0.038$. Moreover, self-perceived disease severity worst ever, fatigue degree, and the daily corticosteroid dose proved to be predictors of high self-reported lupus disease severity: OR (95% CI) 2.13 (1.15–3.94), 1.10 (1.02–1.19), and 1.11 (1.02–1.21), respectively. However, the SLE disease activity (assessed by the SLAM score), the overall damage (estimated by the SLICC index), the association of antiphospholipid syndrome, or the articular impairment was not independent predictors of high self-perceived severity in multivariate analysis (Tables 1, 2).

Table 2 Predictors of higher self-perceived disease severity in systemic lupus erythematosus

Characteristic	Multivariate analysis	
	OR [95% CI]	*p* value
1–10 NRS worst ever	2.13 [1.15–3.94]	0.017
SLAM score, points	1.12 [0.94–1.34]	0.190
SLICC index, points	1.04 [0.63–1.72]	0.876
FACIT-fatigue scale, points	1.10 [1.02–1.19]	0.018
Anxiety/depression disorder, yes/no	6.67 [1.11–39.97]	0.038
Antiphospholipid syndrome, yes/no	2.75 [0.56–13.47]	0.212
Joint anytime, yes/no	6.13 [0.50–74.97]	0.156
Corticosteroids daily dose, mg	1.11 [1.02–1.21]	0.020

Binary logistic regression by enter method

OR odds ratio, *95% CI* 95% confidence interval, *1–10 NRS* 1 to 10 numerical rating scale, *FACIT* fatigue functional assessment of chronic illness therapy fatigue scale, *SLAM* systemic lupus activity measure, *SLICC* systemic lupus international collaborating clinics

p value significant < 0.05

Discussions

The present research analyzed the self-perceived disease severity in women with SLE, drawing attention to the impact of SLE on the affected women's life. In assessing and managing SLE patients, alongside parameters such as objective disease assessment by disease activity score, association of the antiphospholipid syndrome and overall organ damage, considered essential by physicians, attention should also focus on criteria like fatigue degree or depression—anxiety occurrence, that are important for the patients' well-being. Physicians should always also consider patients' previous experience with SLE pathology, since it has an important impact on the current perspective, and objective explanations and reassurance in this regard should be readily provided when needed.

SLE disease evolution is not uniform; there are periods of remission as well as of active disease. Due to the great variability not only between different lupus patients but also within the same case over time, there are no universal accepted definitions of SLE activity, either flare or remission [19, 20]. SLE disease is described like an experience of setback-in-life, with important impact on the patients' lives that need to "move with the waves of SLE" [10].

Previous studies showed that the results of direct measurement of quality of life with simple tools such as VAS were similar to indirect methods like EuroQol Scale and the use of a VAS from 0 to 100 proved to be a reliable measure of patients' health status [21]. In our study, we started from a simple one up to ten NRS on which patients have chosen a number, according to their perception of disease severity: anytime from the SLE diagnosis until inclusion (1–10 NRS worst ever) and at enrollment (1–10 NRS now). The vast majority of the enrolled women quantified the worst moments of their disease as severe or very severe: 29% responded with 7 or 8, while 55% with 9 or 10 on 1–10 NRS overall. These results should raise awareness of burden concerning lupus occurrence in women's life. Moreover, the generally higher self-perceived disease severity proved to have impact on the self-reported disease severity at present.

The patients' and physicians' perceptions concerning disease management are different [22] and it looks like SLE patients and their physicians do not always evaluate disease activity similarly [7]. Physicians-to-be had more negative perceptions upon SLE disease than the patients [23]. On the contrary, physicians' assessment correlated better with disease severity [7], while patient-completed instrument results were not necessarily correlated with lupus activity, but rather reflected the health status changes overall [8]. Physicians' judgment is mainly based on laboratory results or lupus signs and symptoms, while patients' perception is determined by physical and also psychological well-being [24]. Patients might evaluate higher lupus activity than physicians when they present with thrombocytopenia, arterial hypertension, or impairment of daily activities [7] and also when their life is immediately affected [25]. Physicians evaluated as more severe the cases associating proteinuria, hemolysis, use of immunosuppressive drugs, tiredness, or photosensitivity [7]. Another research identified pain, fatigue, photosensitivity, mood disorder, renal damage, poor concentration, and memory loss as most frequently self-reported health problems [26].

Our study also assessed which SLE disease organ impairments might have the highest impact on patients' perception regarding disease severity. The joint involvement, not necessarily labeled as active at enrollment, but counted as additive criteria for the SLE disease classification, was more prevalent in patients with higher self-reported disease severity. This is similar to the results of other researches. A study that included patients with different rheumatic diseases found divergent responses in patients vs physicians only in regard to two items, fatigue, and pain [6]. In SLE, pain, fatigue, and the musculoskeletal impairment were also the most frequent patient-reported symptoms [27]. Found in up to 80% of the SLE patients, fatigue has negative impact on daily activities and quality of life [27], but the lupus disease activity impact on fatigue occurrence is still a topic of debate [28, 29].

Psychiatric disorders such as depression could also influence SLE patients' illness perception [30]. Depression and anxiety have a common occurrence in SLE patients [31, 32]. Several lupus-dependent factors that may cause it have been identified, like anti-N-methyl-D-aspartate (NMDA) or antiribosomal P antibodies [33]. There is also a direct impact of the corticosteroid treatment [34] and most probably of the SLE burden itself on the anxiety and depression appearance. Their occurrence proved here to be predictor of high self-rated disease severity even after adjustment for disease severity score or for the corticosteroid use and these results should raise the rheumatology physicians' awareness for closely following these disorders' management.

Not only the disease's clinical manifestations influence the perception of disease but also the treatment. The patients' compliance for an immunosuppressive therapy (such as Cyclophosphamide and Azathioprine) in lupus is related to their knowledge of these therapies' spectrum of actions [35]. The treatment with immunosuppressive drugs influences not only patients' perception of their illness, but also the physicians'. Doctors considered higher disease activity in patients receiving such treatment [7]. Corticosteroid use is associated with numerous adverse effects. One study of self-administrated questionnaires associated the corticosteroid intake with low quality of life [36]. In our research, not the length of the administration, but the daily steroid dose was related to patient's self-perceived severity, results that most probably reflect that patients are aware that the daily corticosteroid posology is dictated by the disease severity itself.

This research includes several limitations. It is a cross-sectional study and some data were registered retrospectively (i.e., treatment history). For the self-reported disease severity, we used a non-validated tool with an arbitrary cutoff based on descriptive statistics, a simple 1–10 NRS in regard to disease severity at inclusion and in the worst moment during lupus evolution. Even if lupus evaluation scores were prospectively completed, their complexity makes them sometimes difficult to assess (e.g., neurological involvement) and some of the items are subjective, relying on the patients' reported symptoms [19]. However, the disease scores were completed in the same way in all patients and independent of the 1–10 NRS answers.

To the best of our knowledge, there are no previous published researches focusing on self-reported disease severity using a 1–10 NRS in lupus. In addition, an important number of SLE-related parameters were recorded and analyzed, and therefore, the main factors related to patients' self-perceived severity were evaluated.

Conclusions

In sum, our study provides evidence that self-reported disease severity in SLE has several determinants. Fatigue has a negative impact on self-rated disease severity as does the occurrence of psychiatric disorders like depression and anxiety. The patients' self-reported disease severity is also influenced by their daily dose of corticosteroids. A great majority of the women included acknowledged severe and very severe lupus-related events during disease history.

Author contributions AD proposed and conceived the research. All authors contributed equal to data processing and to the article draft. All authors approved the final version and the manuscript submission.

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Compliance with ethical standards

Conflict of interest All authors declare that there is no direct conflict of interest regarding this research. Author AD declares that she has no conflict of interest. Author SC has received a speaker honorarium from Roche and UCB Pharma. Author CD declares that she has no conflict of interest. Author RI has received a speaker honorarium from MSD, Novartis, and Pfizer. Author CJ has received a speaker honorarium from Astra Zeneca, Boehringer Ingelheim, and Bayer. Author CB declares that she has no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Availability of data and materials Data used to support the findings of this study are included within the article. Any other additional data are available from the corresponding author upon request.

References

1. Fatoye F, Gebrye T, Svenson LW (2018) Real-world incidence and prevalence of systemic lupus erythematosus in Alberta, Canada. Rheumatol Int 38(9):1721–1726
2. Mahieu M, Yount S, Ramsey-Goldman R (2016) Patient-reported outcomes in systemic lupus erythematosus. Rheum Dis Clin North Am 42(2):253–263
3. Kiani AN, Strand V, Fang H, Jaranilla J, Petri M (2013) Predictors of self-reported health-related quality of life in systemic lupus erythematosus. Rheumatology 52(9):1651–1657
4. Björk M, Dahlström Ö, Wetterö J, Sjöwall C (2015) Quality of life and acquired organ damage are intimately related to activity limitations in patients with systemic lupus erythematosus. BMC Musculoskelet Disord 16(1):188
5. Boomsma MM, Bijl M, Stegeman CA, Kallenberg CGM, Hoffman GS, Tervaert JWC (2002) Patients' perceptions of the effects of systemic lupus erythematosus on health, function, income, and interpersonal relationships: a comparison with Wegener's granulomatosis. Arthritis Rheum 47(2):196–201
6. Castrejón I, Yazici Y, Samuels J, Luta G, Pincus T (2014) Discordance of global estimates by patients and their physicians in usual care of many rheumatic diseases: association with 5 scores on a Multidimensional Health Assessment Questionnaire (MDHAQ) that are not found on the Health Assessment Questionnaire (HAQ). Arthritis Care Res (Hoboken) 66(6):934–942
7. Leong KP, Chong EYY, Kong KO, Chan SP, Thong BYH, Lian TY et al (2010) Discordant assessment of lupus activity between patients and their physicians: the Singapore experience. Lupus 19(1):100–106
8. Jolly M, Kosinski M, Garris CP, Oglesby AK (2016) Prospective validation of the lupus impact tracker: a patient-completed tool for clinical practice to evaluate the impact of systemic lupus erythematosus. Arthritis Rheumatol 68(6):1422–1431
9. Stoll T, Sutcliffe N, Mach J, Klaghofer R, Isenberg DA (2004) Analysis of the relationship between disease activity and damage in patients with systemic lupus erythematosus–a 5-yr prospective study. Rheumatology 43(8):1039–1044
10. Larsen JL, Hall EOC, Jacobsen S, Birkelund R (2018) The existential experience of everyday life with systemic lupus erythematosus. J Adv Nurs 74(5):1170–1179
11. Palominos PE, Gasparin AA, de Andrade NPB, Xavier RM, da Silva Chakr RM, Igansi F et al (2018) Fears and beliefs of people living with rheumatoid arthritis: a systematic literature review. Adv Rheumatol 58(1):1
12. Phuti A, Schneider M, Tikly M, Hodkinson B (2018) Living with systemic lupus erythematosus in the developing world. Rheumatol Int 38(9):1601–1613
13. Hjermstad MJ, Fayers PM, Haugen DF, Caraceni A, Hanks GW, Loge JH et al (2011) Studies comparing numerical rating scales, verbal rating scales, and visual analogue scales for assessment of pain intensity in adults: a systematic literature review. J Pain Symptom Manage 41:1073–1093
14. Chien C-W, Bagraith KS, Khan A, Deen M, Strong J (2013) Comparative responsiveness of verbal and numerical rating scales to measure pain intensity in patients with chronic pain. J Pain 14(12):1653–1662
15. Petri M, Orbai AM, Alarcon GS, Gordon C, Merrill JT, Fortin PR et al (2012) Derivation and validation of the systemic lupus international collaborating clinics classification criteria for systemic lupus erythematosus. Arthritis Rheum 64(8):2677–2686
16. Bertoli AM, Alarcón GS, McGwin G, Fernández M, Bastian HM, Fessler BJ et al (2006) Systemic lupus erythematosus in a multiethnic US cohort (LUMINA) XXVII: factors predictive of a decline to low levels of disease activity. Lupus 15(1):13–18
17. Gladman D, Ginzler E, Goldsmith C, Fortin P, Liang M, Urowitz M et al (1996) The development and initial validation of the Systemic Lupus International Collaborating Clinics/American College of Rheumatology damage index for systemic lupus erythematosus. Arthritis Rheum 39(3):363–369
18. Kosinski M, Gajria K, Fernandes A, Cella D (2013) Qualitative validation of the FACIT-Fatigue scale in systemic lupus erythematosus. Lupus 22(5):422–430
19. Mikdashi J, Nived O (2015) Measuring disease activity in adults with systemic lupus erythematosus: the challenges of administrative burden and responsiveness to patient concerns in clinical research. Arthritis Res Ther 17(1):183
20. Schneider M, Mosca M, Pego-Reigosa JM, Hachulla E, Teh L-S, Perna A et al (2015) Understanding remission in real-world lupus patients across five European countries. Lupus 25(5):505–512
21. Wang S, Hsieh E, Zhu L, Wu B, Lu L (2015) Comparative assessment of different health utility measures in systemic lupus erythematosus. Sci Rep 5:13297
22. Georgopoulou S, Prothero L, D'Cruz DP (2018) Physician–patient communication in rheumatology: a systematic review. Rheumatol Int 38(5):763–775
23. Nowicka-Sauer K, Pietrzykowska M, Banaszkiewicz D, Hajduk A, Czuszyńska Z, Smoleńska Ż (2016) How do patients and doctors-to-be perceive systemic lupus erythematosus? Rheumatol Int 36(5):725–729
24. Neville C, Clarke AE, Joseph L, Belisle P, Ferland D, Fortin PR (2000) Learning from discordance in patient and physician global assessments of systemic lupus erythematosus disease activity. J Rheumatol 27:675–679
25. Ng X, dosReis S, Beardsley R, Magder L, Mullins CD, Petri M (2018) Understanding systemic lupus erythematosus patients' desired outcomes and their perceptions of the risks and benefits of using corticosteroids. Lupus 27(3):475–483
26. Serrano-Aguilar P, Trujillo-Martin M, del M, Perez, de la Rosa A, Cuellar-Pompa L, Saavedra-Medina H, Linertova R et al (2015) Patient participation in a clinical guideline development for systemic lupus erythematosus. Patient Educ Couns 98(9):1156–1163
27. Pettersson S, Lövgren M, Eriksson LE, Moberg C, Svenungsson E, Gunnarsson I et al (2012) An exploration of patient-reported

symptoms in systemic lupus erythematosus and the relationship to health-related quality of life. Scand J Rheumatol 41(5):383–390
28. Fonseca R, Bernardes M, Terroso G, De Sousa M, Figueiredo-Braga M (2014) Silent burdens in disease: fatigue and depression in SLE. Autoimmune Dis 2014:790724
29. Burgos PI, Alarcón GS, McGwin G, Crews KQ, Reveille JD, Vilá LM (2009) Disease activity and damage are not associated with increased levels of fatigue in systemic lupus erythematosus patients from a multiethnic cohort: LXVII. Arthritis Rheum 61(9):1179–1186
30. Barbasio C, Vagelli R, Marengo D, Querci F, Settanni M, Tani C et al (2015) Illness perception in systemic lupus erythematosus patients: The roles of alexithymia and depression. Compr Psychiatry 63:88–95
31. Kwan A, Katz P, Touma Z (2018) The assessment of anxiety and depression and its associated factors in systemic lupus erythematosus. Curr Rheumatol Rev. https://doi.org/10.2174/1573397114666180926101513
32. Lemaire B, Geron D, Malaise O, Krzesinski JM, Ansseau M, Scantamburlo G (2015) Depression as a common complication of systemic lupus erythematosus. Rev médicale Liège 70:215–218
33. Braga J, Campar A (2014) Biological causes of depression in systemic lupus. Erythematosus Acta Reum Port 39:218–226
34. Huang X, Magder LS, Petri M (2014) Predictors of incident depression in systemic lupus erythematosus. J Rheumatol 41:1823–1833
35. Fraenkel L, Bogardus S, Concato J (2002) Patient preferences for treatment of lupus nephritis. Arthritis Rheum 47(4):421–428
36. Bexelius C, Wachtmeister K, Skare P, Jönsson L, Vollenhoven R van (2013) Drivers of cost and health-related quality of life in patients with systemic lupus erythematosus (SLE): a Swedish nationwide study based on patient reports. Lupus 22(8):793–801