Discrepant Perception of Lupus Disease Activity

A Comparison Between Patients' and Physicians' Disease Activity Scores

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Objective: The aim of this study was to compare patient and physician (MD) assessment of disease activity in systemic lupus erythematosus patients.

Methods: This cross-sectional study was conducted between August 2016 and December 2017 at 2 Peruvian hospitals. One group assessed disease activity using a visual analog scale (VAS, 0–100 mm) and the other one using a numerical rating scale (NRS, 0–4), before and after their MD's visit. MDs assessed it with the Mexican Systemic Lupus Erythematosus Disease Activity (Mex-SLEDAI) (0–32) and with the SLICC/ACR Damage Index (SDI) for damage. Health-related quality of life was ascertained with the LupusQoL. Visual analog scale and NRS were compared using the Wilcoxon signed-rank test and the correlation between disease activity as assessed by the patient and the Mex-SLEDAI, SDI, and LupusQoL with the Spearman rank correlation.

Results: Two hundred forty patients were included; mean (SD) age at diagnosis was 34.9 (12.9) years; most patients were Mestizo. Disease duration was 10.1 (7.0) years. The Mex-SLEDAI was 1.9 (2.7) and the SDI 1.2 (1.5). Disease activity as assessed by the patient, either by VAS or NRS, did not correlate with the Mex-SLEDAI or the SDI. In contrast, patient assessment of disease activity, by VAS or NRS, significantly correlated with several components of the LupusQoL (physical health, pain, planning, emotional health, and fatigue).

Conclusions: Physician's and patient's assessments of disease activity are discrepant; overall, patients score higher than their MDs. Patients score how they perceive the disease is affecting them, rather than disease activity per se. The VAS could be more useful than the NRS as a measurement of disease activity.

Key Words: systemic lupus erythematosus, disease activity, patient-reported outcome, damage, HRQoL

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Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that predominately affects women[1]; it carries unacceptably high morbidity and mortality rates and has a negative impact on the patients' health-related quality of life (HRQoL).[2] The course and outcomes of this disease vary depending on the racial/ethnic background and socioeconomic status (SES) of the affected populations. A less favorable socioeconomic-demographic structure and an earlier age at onset are factors that contribute to a more active SLE.[3]

Factors considered by physicians and patients when evaluating disease activity differ. Patients may be influenced by psychological and physical factors as well as by their present or past personal experiences in their assessment of the activity of their disease; in fact, patients tend to emphasize the psychological aspects of their illness. Physicians, on the other hand, base their assessments of disease activity on the patient symptoms, physical findings, and the results of laboratory assessments.[4] Understanding discordance will help to sensitize physicians to the needs of their patients and to strengthen the patient-physician relationship.[5]

The primary objective of this study was to compare patient and physician (MD) assessment of SLE disease activity in Peruvian patients with SLE from 2 major hospitals; to this end, patients used 2 different scales to assess their disease activity while at the same time they also assess their HRQoL.

METHODS

Patients

We enrolled 240 SLE patients from 2 hospitals in Lima, Perú, one from the Social Security Administration and the other from the Public Health System, Hospital Guillermo Almenara Irigoyen and Hospital Nacional Cayetano Heredia, respectively. Patients from the first hospital were members of the Almenara Lupus Cohort, which includes a comprehensive care program with regular measures of disease activity, damage, HRQoL, systematic evaluation of comorbidities, and educational activities[6]; in contrast, patients from the second hospital receive standard of care in the outpatient clinics but are not subjected to answer any specific questionnaires or measurements. All patients fulfilled the 1982/1997 American College Rheumatology (ACR) criteria for SLE.[7,8] Data collection was cross-sectional, and data were obtained between August 2016 and December 2017. Each hospital's institutional review board approved the study. Patients who signed the informed consent were evaluated with a common protocol, which included an interview, medical records review, physical examination, and laboratory tests.

Variables

Demographic data included age at diagnosis, sex, SES, and ethnicity; SES was defined using the Graffar's method,[9] and ethnicity was self-reported and categorized as white, Mestizo, African Latin-American, Indigenous (Native American), Asian, and other.

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Clinical variables included disease duration, disease activity (ascertained with the Mexican Systemic Lupus Erythematosus Disease Activity [Mex-SLEDAI]),[10] and disease damage (ascertained with the SLICC/ACR Damage Index [SDI][11]). In addition, patients were randomized in 2 groups, one group (n = 120) assessed disease activity using a visual analog scale (VAS) and the other one (n = 120) using a numerical rating scale (NRS) before and after their clinical encounter either with a 100-mm anchored VAS where 0 is no disease activity and 100 is the most disease activity possible or with an NRS where 0 is no disease activity and 4 is the most disease activity possible. Health-related quality of life was assessed with the LupusQoL, using the validated Spanish language version for Perú. This questionnaire includes 34 items on 8 domains, including physical health, emotional health, body image, pain, planning, fatigue, intimate relationships, and burden to others. The domain scores ranged from 0 to 100, with 100 being the highest HRQoL.[12]

Statistical Analyses

Values for categorical variables are given as numbers (percentages), and values for continuous variables are given as means and standard deviations (SDs). Correlations between patient assessment of disease activity, the Mex-SLEDAI, SDI, and LupusQoL were performed using lineal or Poisson regression models, using the Bonferroni correction for multiple comparisons. A $p < 0.05$ (2-sided) was considered significant in all analyses. To evaluate if the presence or absence of SLE disease activity (determined by the Mex-SLEDAI) affected the correlation between patient assessment of disease activity and HRQoL, lineal regression models evaluating the interaction were performed. Similarly, to evaluate the impact of disease duration on these associations, lineal regression models were performed adjusted for the interaction of disease duration dichotomized into 5 years or less or more than 5 years. All statistical analyses were performed using SPSS v. 21.0 (IBM, Chicago, IL).

RESULTS

A total of 240 SLE patients were included, and their sociodemographic and clinical features were comparable at the 2 study sites. The patients mean (SD) age at diagnosis was 34.9 (12.9) years; nearly all patients were Mestizo. Disease duration was 10.1 (7.0) years. The Mex-SLEDAI was 1.9 (2.7) and the SDI 1.2 (1.5). These features were similar for patients from both hospitals. Disease activity as assessed by the patient before and after the MD evaluation, was 29.3 (26.5) and 26.5 (24.9) by VAS and 1.5 (1.2) and 1.4 (1.1) by NRS, respectively. Sex and age were not associated with the patients' perception of disease activity.

Only VAS patients' evaluations of disease activity correlated with the Mex-SLEDAI after MD's assessment (B: 0.02 [0.01]; $p = 0.045$). On the other hand, there was correlation between NRS and the SDI before and after MD's evaluation being the SDI lower in those patients with a lower NRS. Likewise, disease activity as assessed by the patients either by VAS or NRS correlated with several components of the LupusQoL, and that was the case either if assessed before or after the MD's evaluation.

Among those patients (n = 120) who used the VAS to assess their disease activity, the Mex-SLEDAI was 0 in 57 (46.7%) and greater than 0 in 63 (53.3%). In addition, among those patients who assessed their disease activity using the NRS (n = 120), 64 (52.9%) had a Mex-SLEDAI = 0 and 56 (47.1%) had a Mex-SLEDAI ≥ 0.

Interaction between disease activities measured by the patients before MD's evaluation using VAS presented a statistically significant interaction with the disease duration 5 years or less in the physical health and pain domain being higher in those with shorter disease duration (data not shown).

Interaction between disease activities measured by the patients after MD's using NRS presented a statistically significant interaction with the disease duration 5 years or less in the planning domain, being higher in those with shorter disease duration (data not shown).

There were not interactions between disease activities measured by the patients and by the physician (Tables 1, 2).

DISCUSSION

Physician-patient discrepancies in their assessment of disease reflect differences perceptions in terms of both treatment and outcome, which have implications for treatment goals and adherence.[13] The divergent perspectives held by physicians and patients also have implications for the interpretation of outcome measures data.[14]

The VAS is an unidimensional measure of symptoms intensity, which has been used in diverse adult populations, including those with autoimmune diseases.[15–17] It is a widely used tool that allows capturing small changes in measurements, which is not the case with the NRS.[18] Compared with the NRS, the VAS has a small margin of difference.[19]

Ward et al[20] have shown that the Systemic Lupus Activity Measure (SLAM) correlates better with the patient assessment of disease activity and has a better sensitivity to change than the SLEDAI probably because the SLAM includes fatigue as one of its components. In addition, constitutional and musculoskeletal components were those that correlated best with the patients' VAS in the study by Neville et al; fatigue, weight loss, and arthralgias were the symptoms included. The differences between physicians and patients lie in what is not seen, underreporting or ignoring information by either patients and/or physicians.[4]

Disease activity is qualified differently by patients and physicians. Patients approach the disease subjectively, whereas physicians approach it objectively. For example, in the LUMINA study, Alarcón et al found a 58% discrepancy on the assessment of disease activity between patients and physicians. Abnormal laboratory findings were associated with discrepancy regarding physicians who rated it higher, whereas poor self-perceived functioning and joint involvement were associated with discrepancy regarding patients who rated it higher.[21] Golder et al[22] found that patients' predominant concern centers on function and fatigue, whereas physicians' concerns focus on SLE-related organ complications. Moreover, some factors may alter the patient's focus such as length of illness; there is no good correlation between physicians and patients in the assessment of disease activity in patients with a relatively short disease duration.[23] Furthermore, in the study by Askanase, the NRS only correlated with the SLAM in those patients with few symptoms.[24] The VAS is neither affected by the patients' sex or age nor by the pain's etiology.[25] In our analyses, only VAS after MD's encounter was barely associated with Mex-SLEDAI, which is consistent with previous reports.

SLICC/ACR Damage Index was lower in those patients with a lower NRS, which has not been previously reported. However, SDI was not associated with the VAS. These differences between the NRS and the VAS and the association with the SDI and the Mex-SLEDAI could be explained by the lower capability of NRS for capturing small changes, compared with VAS.

We also examined the interaction of disease duration on the patients' assessment of disease activity. Using a cutoff of 5 years, we observed that the shorter the disease duration, the greater the association of active disease with a poor quality of life. Jiang et al[26] found that SLE patients with a disease duration between 12 and 24 months had higher scores in the Systemic Lupus Erythematosus–Specific QoL Questionnaire than those with less than 6 months;

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TABLE 1. Correlation Between Disease Activity as Assessed by the Patient by VAS, Before and After MD Evaluation and Damage (SDI) and the LupusQoL Domains

	Mex-SLEDAI B (SE)	SDI B (SE)	PH B (SE)	Pain B (SE)	Planning B (SE)	IR B (SE)	BO B (SE)	EH B (SE)	BI B (SE)	Fatigue B (SE)
VAS_{pre}	0.01 (0.10); $p = 0.171$	0.00 (0.00); $p = 0.611$	−0.41 (0.08); $p < 0.001$	−0.33 (0.09); $p < 0.001$	−0.31 (0.09); $p < 0.001$	−0.25 (0.17); $p = 0.139$	−0.32 (0.10); $p = 0.002$	−0.30 (0.10); $p = 0.004$	−0.07 (0.11); $p = 548$	−0.41 (0.08); $p < 0.001$
VAS_{post}	0.02 (0.001); $p = 0.045$	0.00 (0.01); $p = 0.949$	−0.36 (0.09); $p < 0.001$	−0.35 (0.10); $p < 0.001$	−0.29 (0.10); $p = 0.002$	−0.318 (0.18); $p = 0.072$	−0.22 (0.11); $p = 0.053$	−0.34 (0.11); $p = 0.002$	−0.04 (0.12); $p = 0.747$	−0.37 (0.09); $p < 0.001$

PH indicates physical health; IR, intimate relationship; BO, burden to others; EH, emotional health; BI, body image.

however, as we are including patients with a longer disease duration, our population is not comparable with theirs. Zhao et al found in a sample of 109 SLE patients with a mean disease duration of 7 years high levels of anxiety as assessed by the Hospital Anxiety and Depression Scale; newer clinical manifestations and high anxiety levels accounted for their self-perceived disturbed body image.[27] However, Khanna et al[28] found that disease duration (mean disease duration, 5.62 ± 5.14 years) did not affect any of the domains of the World Health Organization Quality of Life–Brief Scale in SLE patients. Furthermore, Gladman et al[29] and Jolly et al[30] have shown that disease duration is not associated with HRQoL.

In addition, we have examined if there was an interaction between patient's assessment and having a Mex-SLEDAI = 0, but we have not found an interaction between these variables in any domain of HRQoL or damage. However, it has been proposed that the notion of remission (according to the physicians) does not necessarily associate with a better HRQoL in all its components as shown by Mok et al[31] in a Chinese population. The impact of fatigue and emotional health in general in those patients without disease activity as assessed by the physicians could explain, at least in part, the discrepancies observed between patients and physician.

As demonstrated in another study, patients' perception of their disease is not consistent with the physician's.[32] Therefore, this study is important for physicians treating lupus patients to understand their expectations about the disease and treatment, which leads to highlighting the importance of multidisciplinary management.

Our study has some limitations: first, its cross-sectional design precluded us to evaluate the impact of these measures on the outcome of the disease; second, as the population was ethnically homogeneous, these data may not be generalizable to patients from other ethnic/racial groups; and third, comorbidities have not been examined so we are unable to determine their possible influence on the results presented. However, our study has an important strength: little has been written about this subject, making our research even more relevant; in addition, we have reported for the first time the association between patient's assessments of disease activity and HRQoL and damage. Thus, we consider these data relevant to report, which should prompt the conduct of longitudinal studies with a larger number of patients to confirm our results.

In conclusion, physicians' and patients' assessments of disease activity are discrepant. Patients' scores, overall, are higher than their MDs. The duration of disease less than 5 years is correlated with the domains of physical health and pain, as well as planning using VAS and NRS, respectively. The VAS seems to correlate better with disease activity, and the NRS seems to be influenced more by the damage. Disease activity, as perceived by patients, represents how they perceive their disease is affecting them and does not necessarily include objective parameters that may influence their health status. These data have implications for treatment adherence. Further studies are needed to develop new patients' disease activity measures.

KEY POINTS

- Physician and patient's assessments of disease activity are discrepant.
- The physician's approach is objective, in contrast to the patient who qualifies his or her state of health subjectively.
- Health-related quality of life influences the patient's perception of their illness.
- Duration of disease impacts the association between disease activity and quality of life.
- Visual analog scale can detect small changes, which would explain its association with disease activity.

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TABLE 2. Correlation Between Disease Activity as Assessed by the Patient by NRS Before and After MD Evaluation and Damage (SDI) and the LupusQoL Domains

	Mex-SLEDAI	SDI	PH	Pain	Planning	IR	BO	EH	BI	Fatigue
NRS pre	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)
0	0.14 (1.03); $p = 0.892$	−1.40 (0.64); $p = 0.029$	27.08 (10.34); $p = 0.009$	40.83 (10.71); $p < 0.001$	51.39 (12.86); $p < 0.001$	58.52 (17.67); $p = 0.001$	17.78 (13.76); $p = 0.197$	32.50 (10.98); $p = 0.003$	16.85 (13.61); $p = 0.216$	37.92 (11.00); $p = 0.001$
1	−0.48 (1.04); $p = 0.643$	−1.65 (0.65); $p = 0.011$	30.33 (10.47); $p = 0.004$	30.89 (10.84); $p < 0.001$	52.03 (13.03); $p < 0.001$	64.58 (17.97); $p < 0.001$	25.86 (13.94); $p = 0.064$	33.28 (11.12); $p = 0.003$	19.97 (13.75); $p = 0.147$	38.78 (11.14); $p = 0.001$
2	−0.47 (1.02); $p = 0.642$	−1.50 (0.64); $p = 0.019$	14.76 (10.20); $p = 0.148$	29.17 (10.56); $p = 0.006$	42.59 (12.68); $p = 0.001$	39.87 (17.34); $p = 0.021$	9.26 (13.57); $p = 0.495$	19.33 (10.82); $p = 0.074$	14.60 (13.37); $p = 0.275$	24.83 (10.85); $p = 0.022$
3	0.38 (1.07); $p = 0.721$	−1.10 (0.67); $p = 102$	14.11 (10.76); $p = 0.190$	21.39 (11.14); $p = 0.055$	38.06 (13.39); $p = 0.004$	50.48 (18.59); $p = 0.007$	16.11 (14.32); $p = 0.261$	17.43 (11.43); $p = 0.127$	11.27 (14.17); $p = 0.426$	18.52 (11.45); $p = 0.105$
4	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
NRS post										
0	−1.51 (1.39); $p = 0.275$	−1.84 (0.86); $p = 0.033$	29.60 (13.87); $p = 0.033$	49.77 (14.18); $p < 0.001$	44.68 (17.61); $p = 0.011$	58.17 (20.25); $p = 0.004$	23.38 (18.37); $p = 0.203$	38.43 (14.76); $p = 0.009$	49.70 (17.62); $p = 0.005$	48.96 (14.58); $p = 0.001$
1	−1.36 (1.40); $p = 0.334$	−2.25 (0.87); $p = 0.010$	28.70 (14.04); $p = 0.041$	50.93 (14.36); $p < 0.001$	49.07 (17.83); $p = 0.006$	56.67 (20.52); $p = 0.006$	31.48 (18.60); $p = 0.091$	39.51 (14.95); $p = 0.008$	58.15 (17.78); $p = 0.001$	52.78 (14.77); $p < 0.001$
2	−1.46 (1.39); $p = 0.295$	−1.94 (0.87); $p = 0.025$	12.77 (13.88); $p = 0.358$	33.26 (14.19); $p = 0.019$	29.76 (17.63); $p = 0.091$	35.67 (20.25); $p = 0.078$	12.14 (18.39); $p = 0.509$	23.22 (14.78); $p = 0.116$	50.15 (17.62); $p = 0.004$	32.20 (14.60); $p = 0.027$
3	−1.94 (1.45); $p = 0.180$	−1.47 (0.90); $p = 0.103$	14.71 (14.45); $p = 0.309$	31.21 (14.77); $p = 0.035$	32.84 (18.35); $p = 0.073$	46.47 (21.23); $p = 0.029$	23.53 (19.14); $p = 219$	25.98 (15.39); $p = 0.091$	51.77 (18.30); $p = 0.005$	33.58 (15.20); $p = 0.027$
4	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.

SDI indicates SLICC/ACR Damage index; PH, physical health; IR, intimate relationship; BO, burden to others; EH, emotional health; BI, body image.

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