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PAPER

Extent and characteristics of self-reported pain in patients with systemic lupus erythematosus

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Objective: Patients' own experiences of subjective symptoms are scarcely covered, and the objective of this study was to investigate the extent and characteristics of self-reported pain in patients with systemic lupus erythematosus (SLE). **Methods:** This study comprised a cross-sectional design where 84 patients with SLE were asked to complete self-assessments: visual analogue scale of pain and the Short-Form McGill Pain Questionnaire. Medical assessments, including ESR, SLAM, SLEDAI, and SLICC, were also performed. **Results:** Of the study population, 24% reported higher levels of SLE-related pain (≥40 mm on VAS). This group had a significantly shorter disease duration, higher ESR, and higher disease activity, according to the SLAM and SLEDAI, compared to the rest of the study population. This group mainly used the words "tender," "aching," and "burning" to describe moderate and severe pain, and they used a greater number of words to describe their pain. Of the patients with higher levels of pain, 70% reported their present pain as "distressing." The most common pain location for the whole patient population was the joints. Patients rated their disease activity significantly higher than physicians did. **Conclusion:** These findings expand the current knowledge of the extent of SLE-related pain and how patients perceive this pain. The results can contribute to affirmative, supportive and caring communication and especially highlight SLE-related pain in patients with a short disease duration and high disease activity. *Lupus* (2013) **22,** 136–143.

Key words: Pain; systemic lupus erythematosus

Background

Systemic lupus erythematosus (SLE) is a chronic, autoimmune, rheumatic disease that occurs in flares and has the potential to affect many organ systems. The pathogenesis is not clearly understood, but genetic predisposition combined with environmental factors, for instance ultraviolet (UV) light, infections, and drugs, may be causes of the disease.[1,2] Patients with SLE may present a wide array of complaints and symptoms. Prominent and common symptoms are fatigue, fever, general malaise, and pain in different parts of the body. Disease severity may vary widely among patients.[2,3] Data on incidence and prevalence are inconsistent across studies, possibly because of genetic and environmental factors as well as different study methodology.[4,5] Incidence in Sweden ranges from 4 to 4.8/100,000 and prevalence ranges from 38.9 to 42/100,000. The disease is more common among females than males, with a ratio of approximately 10:1.[4,5]

Headaches and pain from the musculoskeletal system and the abdomen are commonly reported symptoms in patients with SLE.[6–8] SLE-related pain, as in many other conditions of pain, involves a complex relationship with other symptoms, such as fatigue and depression,[9–11] and this may influence the energy and physical capacity individuals have to perform tasks required for daily living[6,12,13] as well as influencing their perceived quality of life.[9,14] Patients with SLE and pain report that health care providers do not pay sufficient attention to their pain, and directed interventions are scarcely initiated.[15]

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Modified treatment regimens and new potentially active drugs for patients with SLE have been developed during the last decade.[16,17] Because of these changes in medical care, the question arises whether SLE-related pain still is common and prevalent. An update and more detailed knowledge about the extent of pain and pain characteristics in patients with SLE are therefore required. In this study, we investigated the extent of self-reported SLE-related pain and its characteristics as well as complexity regarding disease activity and disease duration.

Patients and methods

This cross-sectional study is a part of the SLE Vascular Impact Cohort (SLEVIC) study[18] in which patients with SLE, according to the 1982 revised American College of Rheumatology (ACR) criteria,[19] aged 18 to 70 years, participated. Of the total cohort, 84 patients were consecutively recruited to the present study. The study was approved by the Stockholm Regional Ethical Review Board, and all participants gave written consent. The study participants were invited to respond to the following questionnaires in connection with the inclusion for the SLEVIC study.

The pain visual analogue scale (VAS)[20–22] ranging from 0 to 100 millimeters (mm) connected to the question "how much pain due to SLE have you experienced on average the last week" was used to measure self-reported pain.

The short-form McGill Pain Questionnaire (SF-MPQ) was used to describe the character of the self-reported pain. In the first part of the questionnaire, the person graded the intensity of perceived pain during the most recent week (0 = none, 1 = mild, 2 = moderate, and 3 = severe) using a number of descriptive words. This provided a total score, as well as scores for sensory and affective indices. In the second part of the questionnaire, the patient estimated the current pain using the VAS, and in the third part of the questionnaire, the patients were asked to check the wording that was the most accurate to describe their perceived pain. The SF-MPQ has previously been used to evaluate different rheumatic diseases and has been used in different languages.[23–25]

The Systemic Lupus International Collaborating Clinics Damage Index, ACR (SLICC/ACR), was used to measure the chronic damage in organ systems associated with SLE, its treatments, and the typical comorbidities in SLE.[26]

The Systemic Lupus Activity Measure (SLAM) and the SLE Disease Activity Index (SLEDAI) were used to measure disease activity.[26] Physicians and patients estimated disease activity on the VAS within the SLAM index. The SLAM was also used to identify the most common location of pain related to SLE.[26] As a supplement to measure disease activity, the erythrocyte sedimentation rate (ESR) according to Westergren's method[27] was used.

Statistical analysis

Descriptive statistical analysis was performed, and data were presented as medians (interquartile range (IQR)) due to non-normal distributed data and ordinal data. Since this study used a descriptive approach, no power calculation was performed. Differences between patient groups were assessed using Chi square/Fischer's exact test, the Sign Test, or the Mann-Whitney U Test, depending on the distribution of the analyzed variable. Spearman rank correlation was used for univariate analysis. p values < 0.05 were considered significant. STATISTICA 10 software (Stat Soft Scandinavia AB, Uppsala, Sweden) was used for statistical analysis.

Results

The study population consisted of 72 (86%) females and 12 (14%) males. For patient characteristics, see Table 1. At the time of this study, no patient had a known fibromyalgia diagnosis. For comparative statistical analysis we chose to divide the patients into two groups according to self-reported SLE-related pain on VAS. Due to the distribution of self-reported SLE-related pain on VAS (Figure 1), two humps interconnected with a bar corresponding to reported SLE-related pain 40–59 mm on VAS was found. Based on this pattern as well as clinical guidelines at Karolinska University Hospital, Stockholm, Sweden for acute, postoperative and cancer-related pain, we chose to use 40 mm as the cut-off value. Patients who estimated their SLE-related pain on VAS at 0–39 mm were named the "low-pain group" and those with a pain VAS 40–100 mm were named the "high-pain group" and accounted for clinically significant pain. The median SLE-related pain on VAS for the low-pain group was 6.5 mm (IQR 1–17.5 mm) and the median for the high-pain group was 70 mm (IQR 62–79 mm). The difference between the low-pain group and the high-pain

Table 1 Characteristics of the study population in the low-pain group and the high-pain group

	Study population, n = *84*	*LPG,* n = *64*	*HPG,* n = *20*	p *value*
Female, *n*/%	72 / 86%	54 / 84%	18 / 90%	0.53
Male, *n*/%	12 / 14%	10 / 16%	2 / 10%	NA
Age, yrs, median, (IQR)	45.9 (32.7–56.95)	45.9 (32.3–56.95)	45.95 (37.05–58)	0.71
Disease duration, yrs, median (IQR)	9 (5–16)	10 (5–17.5)	5.5 (3–9.5)	0.008
Current treatment with oral glucocorticoids, *n*/%	53 / 63%	39 / 61%	14 / 70%	0.46
Current dose of oral glucocorticoids, mg/day, median (IQR)	3.75 (0–7.5)	3.44 (0–6.25)	5.63 (0–10)	0.14
Total dose of oral glucocorticoids last year, gram, median (IQR)	1.55 (0–2.53)	1.46 (0–2.33)	1.87 (0–2.95)	0.35
SLICC, median (IQR)	1 (0–3)	1 (0–2)	1 (0–3.5)	0.21

LPG: low-pain group; HPG: high-pain group; IQR: interquartile range; NA: not applicable because of the small number of men; *n*: number; SLICC: Systemic Lupus International Collaborating Clinics Damage Index; *p* value denotes the difference between the LPG and the HPG.

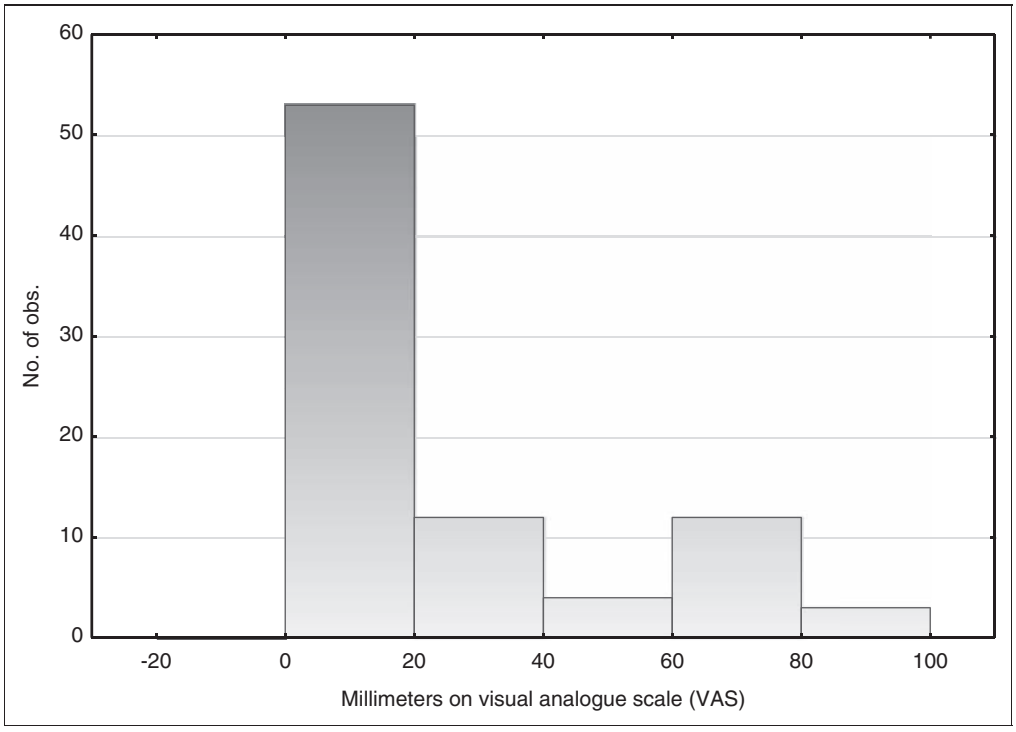

Figure 1 Distribution of sel f-reported SLE-related pain on VAS.

group in SLE-related pain on VAS was significant ($p < 0.001$). The low-pain group consisted of 64 (76%) patients, 54 (84%) females and 10 (16%) males. The high-pain group consisted of 20 (24%) patients, 18 (90%) females and two (10%) males (Table 1). Within the low-pain group, males estimated their disease activity higher compared to females ($p = 0.04$), but there were no other significant sex-related differences in either group. There were no significant differences between the low-pain group and the high-pain group with regard to age, but the high-pain group had significantly shorter disease duration compared to the low-pain group (Table 1).

Of the patients, 63% were currently being treated with oral glucocorticoids. No significant difference in the proportion of patients treated with oral glucocorticoids or in the dose of oral glucocorticoids was found between the low-pain group and the high-pain group (Table 1). There were also no significant differences in the estimated SLE-related pain in the VAS between patients who were and were not treated with oral glucocorticoids (data not shown).

The high-pain group had significantly higher ESR, SLAM, SLEDAI and self-reported disease activity compared to the low-pain group (Table 2). The SLAM scores only indicated

Table 2 Disease activity measured by the SLAM, SLEDAI, ESR and physicians' and patients' estimated disease activity

	Study population, n = *84*	*LPG*, n = *64*	*HPG*, n = *20*	p *value*
SLAM	6 (4–10)	5.5 (4–8)	10.5 (8–14)	<0.001
SLEDAI	3 (0–6)	2 (0–4)	4.5 (2.5–9.5)	0.014
ESR	21 (12–28)	17 (12–26)	27 (13.5–43)	0.044
	Study population	LPG	HPG	p value
Disease activity measured by physicians (VAS mm/SLAM) $n = 27$	8 (3–19)	7 (3–11)	25.5 (13–30)	<0.029
Disease activity measured by patients (VAS mm/SLAM) $n = 81$	19 (10–50)	13 (8–23)	52.5 (41–68.5)	<0.001

Data are presented as median and interquartile range in parentheses. LPG: low-pain group; HPG: high-pain group; SLAM: Systemic Lupus Activity Measure; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; ESR: erythrocyte sedimentation rate; VAS: visual analogue scale; *p* value denotes the difference between the LPG and the HPG.

clinically important disease activity in the high-pain group. SLEDAI scores indicated mild disease activity in both the low- and high-pain group. We also speculated that the patients in the high-pain group may not have received adequate treatment for SLE and, therefore, had more symptoms, such as pain, than patients in the low-pain group with longer disease durations. Correlations between disease duration and the disease activity indices SLAM, SLEDAI, and ESR were also investigated, but no significant correlations were found between those variables (data not shown). In the SLAM, where patients and physicians rated disease activity on the VAS (Table 2), it was found that the patients rated significantly higher values compared to the physicians' values ($p = 0.02$). Disease activity, estimated by the physicians on the VAS within the SLAM, was available in 27 patients. The SF-MPQ was completed by 83 patients. For the low-pain group, the median total intensity score of descriptive words in SF-MPQ was 2.0 (IQR 0.0–5.0), and for the high-pain group, the score was 14.5 (IQR 5.5–20.5). The median sensory index was 2.0 (IQR 0.0–4.0) for the low-pain group, and the high-pain group's index was 13.0 (IQR 7.0–17.0). The median for the affective index was 0.0 (IQR 0.0–1.0) in the low-pain group and 2.0 (IQR 0.0–3.5) in the high-pain group. For all three indices (total, sensory, and affective), there were significant differences between the low-pain group and the high-pain group ($p = 0.001$–<0.001). The median number of descriptive words used to describe the pain was 2.0 words (IQR 0.0–4.0) for the low-pain group and 8.5 (IQR 4.0–10.5) words for the high-pain group. The difference in the number of words between the two groups was significant ($p < 0.001$).

There was a strong correlation between self-reported SLE-related pain on the VAS and the number of descriptive words used ($r = 0.78$, $p < 0.001$). Less than half of the study population ($n = 37/45\%$) recorded "none" (0.0) for the descriptive word "tender." In the high-pain group, the words used most often for moderate and severe pain were "tender," "aching," and "burning." In the low-pain group, the words used often for moderate and severe pain were "tender," "aching," and "stabbing" (Figure 2).

The present pain index (PPI) in the SF-MPQ was completed by 82 patients. In the whole group, 41% used the words "no pain," 24% used the word "mild," 7% used the word "discomforting," 24% used the word "distressing," 1% used the word "horrible," and 1% used the word "excruciating" to describe their pain. In the high-pain group, one patient used the word "horrible" and one used the word "excruciating" to describe their present pain. Most patients (55%) in the low-pain group recorded "no pain" on the PPI. In the high-pain group, 70% recorded their present pain as "distressing" on the PPI (Figure 3).

Since prior studies reported common pain locations in SLE patients, such as musculoskeletal pain, abdominal pain and headaches, the SLAM was used to investigate these potential pain sites. According to the SLAM, abdominal pain, headache, myalgia/myositis, arthralgia, and arthritis were more frequently reported in the high-pain group than in the low-pain group. The most frequently reported pain location in both pain groups was the joints (Figure 4).

Patients who had arthritis had significantly fewer years since their diagnosis (median 3, IQR 1–11) than patients without arthritis (median 9, IQR

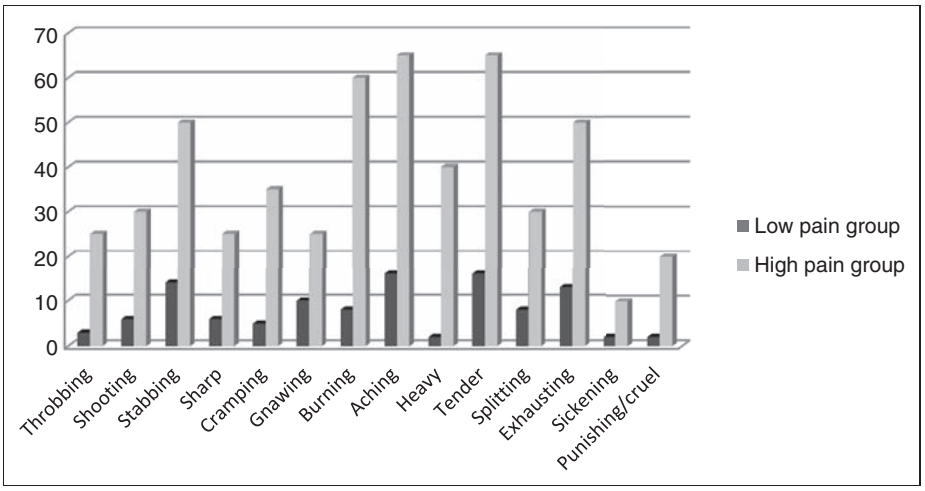

Figure 2 Describing words used in percent to signify moderate and severe pain.

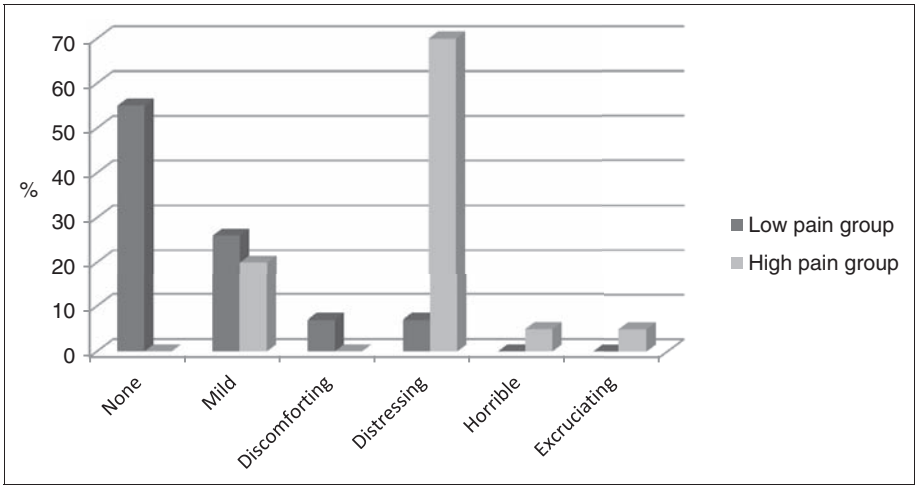

Figure 3 Present pain index (PPI).

5–17.5) ($p = 0.03$). No other significant differences were found for age, ESR, and disease duration between those who had abdominal pain, headache, arthralgia, myalgia/myositis, and arthritis compared to those who did not have these symptoms (data not shown).

Discussion

This study shows that as much as 24% of the SLE study population estimated their disease-related pain at ≥40 mm on the VAS. The median for SLE-related pain on the VAS was 70 mm, which is usually considered as the limit for severe pain, and therefore the pain in this group was judged to range from moderate to severe. This high-pain group had higher self-reported disease activity, higher physician-estimated disease activity, and objective measurements, such as the ESR, SLAM, and SLEDAI. Furthermore, the high-pain group had a shorter disease duration compared to the low-pain group. These results addressed the objectives of the study, and even though we are aware of the small cohort size, several significances were found. Since all patients with SLE in Sweden should be affiliated with a specialized clinic, the cohort was considered to be representative of the disease. The results are therefore judged to be generalizable and it is possible that the significance levels could be even higher in a larger cohort. However, the results do not give any answers about causality of SLE-related pain, which was not the purpose of the study.

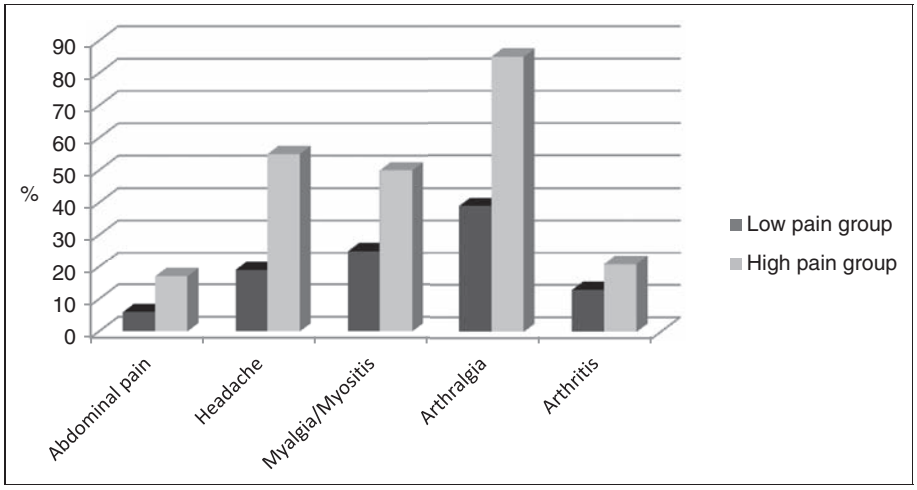

Figure 4 Pain location due to SLAM.

Taken together, these results are consistent with results from a previous study by Cervera et al.[28] that showed a gradual reduction in inflammation over the course of the disease. Another explanation for the higher levels of pain in the early course of the disease could be that patients might not have acquired pain management strategies. Morand et al.[29] concluded that concomitant fibromyalgia in patients with SLE may interfere with the rating of disease activity, and there are theories about common pain-related mechanisms in SLE and fibromyalgia.[30] Since no patient had a known diagnosis of fibromyalgia, we estimated that disease activity was not affected by coexistent fibromyalgia. On the other hand, the patients in this study were not investigated in order to diagnose fibromyalgia.

The statistically significant difference between the low-pain group and the high-pain group, reported on both the SLAM and SLEDAI, supports a hypothesis that SLE-related pain may be related to disease activity, but previous studies illuminate the complexity of the interpretation of the SLAM and SLEDAI.[29,31,32] The results from this study could indicate that the inflammatory activity is not sufficiently controlled and suggest poor management of pain in patients in this SLE cohort.

Interestingly, the patients estimated significantly higher disease activity scores on the VAS within the SLAM than the physicians. The physicians scored disease activity was available for only 27 patients, making comparisons impossible, but disease activity on the VAS, estimated by physicians, has previously been criticized as too blunt,[33] and prior studies show that patients and physicians may rate disease activity differently and on different benchmarks.[34,35] Yen et al.[36] showed that a higher degree of pain correlates to a higher degree of discord between patients and physicians.

With regard to the dosage of oral glucocorticoids, there were no significant differences between the low-pain group and the high-pain group, and no correlation was found between self-reported SLE-related pain and the dosage of oral glucocorticoids. This does not support the impact of glucocorticoids on self-reported SLE-related pain and is also in line with the results from Kozora et al.[37] and Jump et al.[10]

The SF-MPQ is designed to obtain data about the sensory, affective, and overall intensity of pain. One goal of this study was to investigate the characteristics of SLE-related pain. Therefore, not only sensory, affective, and total indices have been presented, but the extent to which the descriptive words for pain have been used is investigated, as suggested by Melzack.[23] The descriptive words used most in the SF-MPQ in both the low-pain group and the high-pain group for moderate and severe pain were "tender" and "aching." The descriptive word "tender" also had a high intensity score and was the word most used among patients with rheumatoid arthritis (RA) and patients with fibromyalgia in an earlier study by Burckhardt and Bjelle.[24] To our knowledge, no previous study has used the descriptive words in the SF-MPQ to investigate the characteristics of self-reported pain in patients with SLE. This new insight into patients' experiences with SLE-related pain may contribute to more affirmative care[38] and, in this way, aim to avoid patients feeling neglected.[15]

The PPI in SF-MPQ showed that one-fourth of the study population, 70% in the high-pain group,

described their present pain as ''distressing.'' These results confirm our hypothesis that SLE-related pain is a clinically significant symptom for which caregivers should create interventions.[6,12]

Both strengths and weaknesses are found in the current study. This study involves a rather small sample of patients; however, several significant findings were discovered, despite the sample size. On the other hand, because of the small sample, further associations might be undetectable. A common problem with SLE studies is the small proportion of males to females. This also applies to the current study, where no differences in estimated SLE-related pain between sexes were found. This study did not decisively determine if SLE-related pain is associated with disease activity. However, the results suggest that accurate pain management strategies could be especially important for patients with newly diagnosed SLE and patients with high disease activity. The results also indicate that patients and physicians may evaluate disease activity in different ways.

Conclusion

This study revealed that patients with SLE-related pain $\geq$40 mm on the VAS had higher values on the disease activity assessments, which is consistent with the hypothesis that disease activity at least contributes to SLE pain. Glucocorticoid treatment did not seem to influence pain.

The results also highlighted the difference between physician and patient assessments of disease activity, which may create misunderstandings, obstruct communication, and could lead to less compliance with treatment. We have also demonstrated that patients with higher levels of pain had shorter disease duration; therefore, special attention concerning pain should be directed at recently diagnosed patients. These patients used a greater number of describing words in the SF-MPQ, and most patients perceived their present pain as ''distressing.'' The increased knowledge about pain characteristics in SLE contributed to a deeper understanding of how patients with SLE experience pain. This finding is important in creating confirming, supportive, and caring communication in rheumatology care.

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Conflict of interest

The authors have no conflicts of interest to declare.

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