



**Karolinska  
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**Institutionen för neurobiologi, vårdvetenskap och samhälle**

**Sektionen för omvårdnad**

## Self-reported pain in SLE

AKADEMISK AVHANDLING

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## ABSTRACT

Systemic lupus erythematosus (SLE) is an autoimmune, rheumatic disease, potentially affecting most organ systems. The disease is commonly considered to be chronic and occurs in often unpredictable flares, with alternating low and high disease activity. SLE predominantly affects females, but incidence and prevalence differs across different populations. Pain in SLE is reported to be a common symptom, and has a complex relationship with impaired health-related quality of life and other symptoms, such as fatigue, anxiety and depression. These may individually or together influence a patient's ability to perform daily activities. Modified treatment regimens and new potentially active drugs for patients with SLE have been developed over the last decade. Considering these changes in medical care, as well as the heterogeneous nature of SLE, the question of whether SLE-related pain is still common remains unanswered. An updated and more detailed knowledge about the extent of pain and pain characteristics are therefore required.

**Aim:** The overall aim of this thesis was to investigate to what extent patients with SLE report disease-related pain, and also to investigate pain characteristics and pain complexity regarding disease duration and disease activity in a cohort of patients with SLE. Fatigue, anxiety, depression and health-related quality of life were investigated in patients recording higher scores of pain intensity, compared to those with lower scores of pain intensity.

**Method:** In this cross-sectional cohort study, 84 patients with SLE and 91 age and sex-matched controls from the general population completed self-assessment measures and questionnaires regarding pain (VAS and SF-MPQ), fatigue (MAF), health-related quality of life (SF-36), and anxiety and depression (HADS). In addition, data on age, disease duration, disease damage and disease activity were collected, as well as treatment with glucocorticoids. Based on pain intensity scores through VAS, the patients were dichotomized into two groups, the low-pain group and the high-pain group. A cut-off value, 40 millimetres, was chosen due to the distribution of scores in VAS.

**Results:** The high-pain group constituted 24% of the SLE-cohort and was characterized by significantly shorter disease duration and higher disease activity compared to the low-pain group. In the high-pain group, 70% scored present pain as *distressing*. The high-pain group also used significantly more words in SF-MPQ compared to the low-pain group. The words most used to describe 'moderate and severe' pain were *aching, burning, tender* and *stabbing*. The most common pain location in both groups was joints. Treatment with glucocorticoids did not differ between the two groups, and patients treated or not treated with glucocorticoids did not differ in pain-intensity scoring. The high-pain group reported significantly impaired quality of life, higher scores of fatigue, anxiety and depression compared to the low-pain group and control group. The low-pain group did not differ significantly from controls regarding pain, fatigue, anxiety and depression.

**Conclusion:** The results show that pain in SLE is still a significant problem for a substantial proportion of patients. Higher levels of disease-related pain from SLE indicate great symptom burden regarding impaired health-related quality of life, fatigue, anxiety and depression, despite mild to moderate disease activity. Identification and focusing on patients with higher scores of self-reported pain, especially patients with short disease duration, seems crucial in order to reduce symptom burden and alleviate suffering.

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