Institutet, Department of Medicine Solna, Stockholm, Sweden; Karolinska Institutet, Department of Medicine Solna, Stockholm, Sweden; Karolinska Institutet, Department of Medicine Solna, Stockholm, Sweden.

Background: It is well known that genetic factors and environmental triggers contribute to the inflammatory process and onset of systemic lupus erythematosus (SLE). Yet, other contributors may still be unknown, and few studies have to date systematically explored patients’ views on what caused SLE onset. In a longer perspective, we also need to pay more attention to health literacy, and to patients’ understanding of their disease since these aspects are important for treatment compliance and patients’ perception of health and patient education.

Objectives: To explore patients’ thoughts of the cause of SLE and to analyse their reports in relation to perceived health and quality of life.

Methods: Adult patients with SLE (≥ 4 ACR criteria) recruited to a cohort study in tertiary care. The participants answered the written question “Do you have any thoughts of why you got SLE?” and additional questions of perceived SLE activity during the last three months (score 0-10, 0= no activity), SLE health last week (score 0-100, 0=good SLE health) and current general health (score 0-100, 100=full health). The participants’ free written answers were categorized according to the content. We explored if patients’ age, educational level, disease duration as well as perceived health differed between the categories.

Results: 375 patients were included. The main question regarding their thoughts of why they got SLE was commented by 290 patients (77%), mean age 48 years, range 18-87, mean disease duration 15 ±14 years. The replies on the health scales ranged from minimum till maximum. SLE activity was low to moderate (mean 4.2 ±3), perceived SLE health mean 34.7 ±25.9 and current general health mean 63.1 ±21.0. The highest reported level of education was university education for 47% and high school for 36%. Among the patients who answered the main question (n=290), 33% (n=95) answered that they had no idea/thoughts of why they got SLE. Men (p= 0.041) and persons with lower educational level (p = 0.038) were more common in this group, also reporting slightly better general health (p= 0.050) than the group that had explicit thoughts of why they got SLE. Age, disease duration or perceived SLE parameters did not differ between the two groups. The answers of patients’ thoughts of why they got SLE were sorted into categories: genetics (n=82), stress/trauma (n=65), infections/immunizations (n=36), hormones/treatment (n=28), lifestyle behavior (n=28), treatment/disease other than SLE (=26) and environmental factors (n=5). A majority (n=135, 69%) wrote one potential factor of why they got SLE, two factors were reported by 49 patients (25%), one patient wrote five potential reasons. It was exclusively answers from women that could be categorized as “hormones/treatment” or “treatment/diseases other than SLE” and only one man wrote a statement of stress/trauma as potential trigger of SLE. Patients in the category “hormones/treatment” had shorter disease duration (p=0.029), higher perceived SLE activity (p=0.011) and worse general health (p= 0.002) compared to those that had no statement that could be sorted into the category. Only five patients reported environmental triggers and these perceived worse SLE health (p= 0.022) and worse general health (p=0.038). Patients who reported stress/trauma as potential triggers of SLE onset had in a larger extent university education (p= 0.027) than those who did not report stress/trauma as a trigger.

Conclusion: Beside genetic factors, a prominent number of patients in this study reported stress/trauma or hormones as important triggers for developing SLE.

In these groups perceived health and educational levels had different patterns. Additionally, infections/immunization were perceived as triggers for SLE but without the same difference in perceived health or educational level. Further studies should extend these results and investigate patients’ perceptions of triggers for SLE flares, and high disease activity, information which can enhance our understanding of factors that may contribute to important aspects of SLE and patients’ perceptions of health.