Purpose Our aim was to study the delay from the onset of symptoms to the diagnosis of systemic lupus erythematosus (SLE) and its association to the outcome of the disease.

Methods Information on demographics, onset of first symptoms, first physicians visit and time of diagnosis was assessed by self-reported questionnaires among SLE patients in Germany in 2010 (LuLa cohort, n=585). Disease activity (Systemic Lupus Activity Questionnaire; SLAQ), disease related damage (Brief Index of Lupus Damage; BILD) and health related quality of life were chosen as relevant proxies for outcome. Linear regression analysis was used to analyze the association to the outcome of the disease, adjusted for age, disease duration and sex.

Results Mean reported duration between the onset of symptoms and the diagnosis of SLE was 45.7 months (SD 72.6), including a mean duration of 13.2 month (SD 40.9) between the onset of symptoms and the first physicians visit. In our cohort, the mean disease duration was 17.7 years (SD 7.89). A delayed diagnosis was associated with high disease activity (SLAQ, p<0.0001, \( \beta =0.199 \), corr. \( R^2 =0.068 \)), high disease-related damage (BILD, \( p=0.002, \beta =0.137, \) corr. \( R^2 =0.163 \)) and low health-related quality of life (SF-12 physical \( p=0.004, \beta =-0.136, \) corr. \( R^2 =0.125, \) SF-12 mental \( p=0.004, \beta =-0.143, \) corr. \( R^2 =0.012 \)) in the year 2010. The organ involvement at the time of diagnosis did not alter these results.

Conclusion The time to diagnosis was associated with a worse outcome in systemic lupus erythematosus, assessed by self-reported questionnaires for disease activity, disease-related damage and quality of life, unaffected by the organ involvement at the time of diagnosis. An early diagnosis should therefore be strive to improve the long-term outcome of the disease.

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