

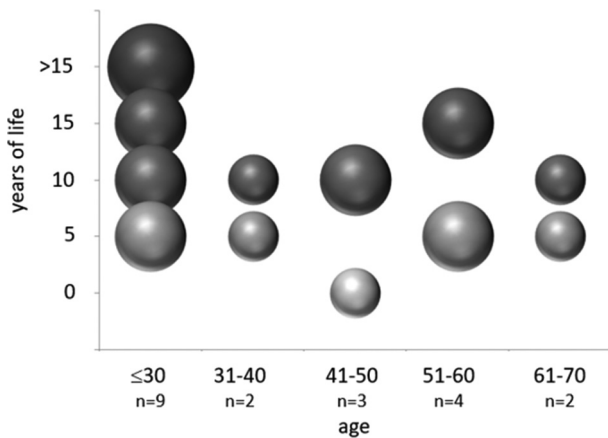
P164 VALUE OF FATIGUE: PATIENTS VS. PHYSICIANS – TIME TRADE-OFF APPROACH

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Introduction Fatigue is a common symptom in SLE patients and often held responsible for their reduced quality of life. With this survey, we wanted to examine the degree of suffering in SLE patients with fatigue and determine, whether they would trade in years in order to live without fatigue or if they would trade in fatigue for other disease manifestations (skin, joints or kidney).

Methods Our survey took place during a meeting with patients from the German SLE self-help community on World Lupus Day, May 10th 2019 in Duesseldorf/Germany. Using Edivote®, an anonymous audience response system, we asked patients: if they had been questioned by their treating physicians about fatigue (1:always, 2:sometimes, 3:never), how



Abstract P164 Figure 1 Results from our time trade-off survey, sorted by patients' age; n=20, absolute numbers; (Size of circles represents 1 patient [small] 2 patients [medium] and 3 patients [large])

many years of life they would sacrifice in order to live without fatigue (0, 5, 10, 15, >15 years, respectively) and if they would trade in fatigue for another disease manifestation (skin, joints or kidney).

Results 26 patients (96.2% female) took part in our survey. Most patients were ≤50 years old (61.5%) with a disease duration of >5 years (81.0%). Six patients were regularly asked about fatigue, four patients were sometimes asked and eight patients had never been asked about fatigue. The results from the time trade-off question are shown in figure 1. Five patients were willing to trade in fatigue for a skin manifestation (consistent redness on exposed skin); one patient wanted to trade in fatigue for a kidney manifestation (50% reduction of kidney function, edema and fluid restriction).

Conclusion In our cohort, 42% of responding patients had never been asked about fatigue. To our surprise, almost all patients were willing to trade in ≥5 years for a life without fatigue. This result underlines patients' degree of suffering and should raise more awareness for SLE patients living with fatigue. Our results clearly indicate the discordant assessment of the importance of fatigue by patients and physicians. These findings with respect to time trade-off should be validated in a larger cohort.

P165 PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS AND LYMPHOMA AT A TERTIARY HOSPITAL

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Background Evidence of an increased risk to develop haematological malignancy, especially non-Hodgkin's lymphoma (NHL) in autoimmune diseases, has been gathered since the 1970s. In the last decade studies from SLE cohorts have consistently shown a markedly increased risk of NHL.

Objectives To analyze clinical and disease characteristics in SLE patients who developed a lymphoma during follow-up, as

Abstract P165 Table 1 Characteristics of SLE patients and treatment at lymphoma diagnosis

n	Manifestations	Haematological	Immunological	Steroid ^a	Antimalarials	Immunosuppressant ^a
1	Rash, photosensitivity, arthritis, pleuritis, pericarditis	Leucopenia	ANA, DNA, SS-A, low C, LA, Anticardiolipin antibodies (IgG)	Yes	No	Azathioprine (AZA)
2	Arthritis	Haemolytic anaemia	ANA, Sm, SS-A	No	Yes	No
3	Rash, photosensitivity, discoid, oral ulcers, pericarditis, headache	Lymphopenia	ANA, RNP	Yes	Previous to lymphoma	No
4	Rash, arthritis, epilepsy, fever, adenopathies	Leucopenia lymphopenia	ANA, DNA, Sm, low C, LA	Yes	Yes	Mycophenolate (MMF) (previous AZA)
5	Discoide, photosensitivity, fever, splenomegaly, hemophagocytic syndrome	Leucolymphopenia thrombocytopenia	ANA	Yes	Previous	Previous cyclophosphamide
6	Oral ulcers, splenomegaly	Platelets <20000, haemolytic anaemia	ANA, SS-A, low C, LA, Anticardiolipin antibodies (IgM)	Yes	No	Rituximab
7	Rash, photosensitivity	Leucopenia lymphopenia	ANA, SS-A, SS-B, low C, LA, Anticardiolipin antibodies (IgM/G)	Previous	Yes	No
8	Arthritis, epilepsy, CNS vasculitis, stroke, pleuritis, pericarditis	Thrombocytopenia	Anticardiolipin antibodies (IgG)	Yes	Previous	No
9	Arthritis, stroke, glomerulonephritis	Haemolytic anaemia, thrombocytopenia lymphopenia	ANA, DNA, RNP, SS-A, low C, Anticardiolipin antibodies (IgG)	Yes	Previous	Mycophenolate (MMF)

^aMean time with immunosuppressant previous to lymphoma was 2 years and 12 years with steroid.

well as to define characteristics of the lymphoma and its evolution.

Methods Retrospective observational, longitudinal study conducted in a tertiary hospital. Medical records of 362 patients with ≥ 4 SLICC classification criteria of SLE were reviewed, including those with lymphoma diagnosis. Demographic and clinical data, comorbidities, SLE manifestations and therapy, data related to lymphoma and outcome were collected. Descriptive statistic analysis with measures of central tendency and measures of variability was performed.

Results Of the 362 SLE patients, 9 (2.5%) were diagnosed of lymphoma, of which 100% female. Mean age at SLE diagnosis was 34 y.o (SD 11) and average duration from SLE diagnosis to lymphoma was 17 years (SD 14). 7 patients were Caucasian and 2 Hispanic. Observed comorbidities were hypertension (67%), diabetes (22%), dyslipidemia (33%), HBV infection (11%) and active smoking (66%). No malignancy history was detected. Most frequent SLE features were haematological (100%), joint (56%) and skin (56%) involvement. The serious ones were: 3 patients with haemolytic anaemia (1 of them, platelets < 20000), 2 epilepsy (1 with CNS vasculitis), 1 glomerulonephritis, 1 pulmonary hypertension and 1 hemophagocytic syndrome. Only 1 patient had overlap with Sjögren's syndrome. At the time of lymphoma diagnosis, 7 patients were on steroids, 4 on immunosuppressants (2 mycophenolate, 1 azathioprine, 1 rituximab) and 3 on antimalarials (table 1). Mean age at lymphoma diagnosis was 51 y.o (SD 10). 5 patients (56%) had diffuse large B-cell lymphoma (DLBCL); 1, NHL; 1, Hodgkin's lymphoma; 1, mantle B-cell lymphoma and; 1, MALT. Only 1 patient, of 4 with available data, had EBV positive in the tissue. 7 patients received chemotherapy and 2 patients completed treatment with autologous peripheral stem-cell transplantation. Three patients died, 2 due to lymphoma and one due to other causes (severe flaccid paralysis). Overall survival after lymphoma diagnosis was 8 years (SD 6).

Conclusion In our patients, unlike that reported in the literature, lymphoma diagnosis was in SLE with longer duration of the disease, and all cases were female. Most frequent subtype was NHL, and all patients had previous haematological manifestations. Regarding previous SLE treatments, 5 patients had been exposed to immunosuppressants.

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POSSIBLE NEW ROLE FOR HCQ IN PREVENTING DEPRESSION IN JSLE?

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Background Hydroxychloroquine (HCQ) is a key immunomodulatory treatment in systemic lupus erythematosus (SLE) with pleiotropic effects. Beyond anti-thrombotic, anti-atherosclerotic and anti-diabetic effects, anti-microbial and anti-cancer are possible roles. Neuropsychiatric symptoms, mostly headaches, depression, anxiety and cognitive impairment, affect nearly half of patients. Several pathways have been identified: antibody-mediated/cytokine-induced neurotoxicity, vasculopathy and loss of neuroplasticity. Thus, we hypothesized if there is a role for HCQ in preventing depression in jSLE.

Methods A cross-sectional sample of juvenile-onset SLE (jSLE) patients, currently aged ≥ 16 years, completed a psychosocial assessment including the SF-36, HADS, SHS, BriefCOPE and MMSE questionnaires, between October 2018- May 2019. Local Ethics Committee approved the study. All patients fulfilled both 2012 and 2019 EULAR/ACR classification criteria for SLE. Juvenile-onset was defined as age at diagnosis < 18 years. Demographics and clinical characteristics were collected. Statistical analysis was performed with SPSS®.

Results 30 jSLE patients were included (90%female) in the study, with median age of 21 years, being the youngest 16 and the oldest 35, with mean (SD) age of diagnosis of 15.8 ± 2.1 . Mean values (SD) of psychosocial assessment were: SHS 5.2 (1.02); MMSE of 27.7 (1.8); Physical health SF-36 of 66.8 (9.9) and Mental health SF-36 of 68.9 (17.5). 23.3% jSLE showed mild cognitive impairment, 63.3% anxiety and 13.3% depression. From the 27 jSLE treated with HCQ, those had better results in the SHS ($p=0.030$) and scored lower in scores in the Hospital Anxiety and Depression scale ($p=0.023$). Interestingly, this also occurs for emotion focused coping, with significantly better results in jSLE taking HCQ ($p=0.001$).

Conclusions Young adults with SLE are at risk for depression and HCQ may have a role in preventing it. Longitudinal studies will permit to confirm present results and clarify the role of coping strategies in the occurrence of depression in jSLE.

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LONG TERM FOLLOW-UP OF LUPUS PATIENTS UNDER ANTIMALARIC TREATMENT: FACTORS OF DROP-OUT

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Background Antimalarials represent the cornerstone of SLE treatment, since its uses control clinical manifestations in many patients, prevents disease flare and permits steroid reduction. The aim of this study is to describe the safety profile and the reasons for discontinuation of antimalarials in patients with SLE and determine which factors act as a predictor of drop-out.

Methods A single centre, retrospective, case control study was performed including patients with SLE according to SLICC 2012 criteria. Clinical and demographical variables were collected. Disease activity was measured with clinical, analytical and disease scores.

Results 66 patients were included, 56 patients (84.8%) were females, the median age was 49.3 years (23.4, 76.2). 95.50% of patients were Caucasian. 11 patients (16.7%) had high blood pressure and 6 (9.1%) diabetes mellitus. The disease duration of SLE had a median of 198 months (5.1, 144.9), and median SLEDAI was 3.4 (2–23). 45 patients (68.2%) were taking steroids and its median dosage was 3,6 (1.2, 2.5) mg. 58 patients received antimalarial treatment during their follow-up with a median exposure time of 354 (6, 867) months. 91.2% took hydroxychloroquine (HCQ), 6.9% chloroquine (CQ), and only one patient mepacrine (1.7%). At least one side effect was reported in 22 patients (33.3%) leading to permanent withdrawal in 13 (19.7%): 7 cases of ocular toxicity, 4 intolerance (6,1%), and 2 cases of inefficacy (3%). 45