the degree of fatigue. More studies are needed to understand the role of this pleiotropic growth factor in self-perceived fatigue in SLE and pSS.

REFERENCES

- [1] Chaigne B, Chizzolini C, Perneger T, Trendelenburg M, Huynh-Do U, Dayer E, Stoll T, von Kempis J, Ribi C, Swiss Systemic Lupus Erythematosus Cohort Study G: Impact of disease activity on health-related quality of life in systemic lupus erythematosus - a cross-sectional analysis of the Swiss Systemic Lupus Erythematosus Cohort Study (SSCS). *BMC Immunol* 2017, 18(1):17.
- [2] Fukushima T, Uchiyama S, Tanaka H, Kataoka H: Hepatocyte Growth Factor Activator: A Proteinase Linking Tissue Injury with Repair. *Int J Mol Sci* 2018, 19(11).

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SAT0206

FACTORS ASSOCIATED WITH HYDROXYCHLOROQUINE USE IN SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS WITH END STAGE RENAL DISEASE

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Background: Hydroxychloroquine (HCQ) use in SLE has been associated with a lower risk of end-organ damage, SLE flares, and thrombosis, with potential mortality benefit among SLE with end stage renal disease (ESRD)^{1, 2, 3}. However, fewer than 30% of SLE continue HCQ after ESRD onset³. On the other hand, there is an increased risk of HCQ toxicity among SLE-ESRD⁴. It has not been studied what factors are associated with HCQ use after ESRD. Understanding these factors may inform future studies assessing the safety and efficacy of HCQ in SLE-ESRD and address the "confounding by-indication" bias (i.e. different treatments are intentionally chosen for patients with different prognoses) when analyzing retrospective data regarding HCQ use in SLE patients with ESRD.

Objectives: To determine the factors associated with HCQ use among SLE patients with ESRD.

Methods: We performed a retrospective chart review of SLE patients with ESRD at a single tertiary care center between 2010-2017. All included patients met ACR and/or SLICC criteria for SLE and had at least one visit with rheumatology, nephrology, or primary care, before and after the development of ESRD. SLE-related symptoms, serologic markers of disease activity, and rheumatology visits were identified, both pre- and post-ESRD onset. Transplanted patients were excluded at the time of their first renal transplant.

Results: A total of 69 patients were included, 58 had pre-ESRD data. Of these patients, 33/58 (57%) were taking HCQ prior to ESRD onset. Following the diagnosis of ESRD, 40/69 (58%) were prescribed HCQ within six months after ESRD onset. Of these, six discontinued HCQ by the last documented visit, and one patient initiated HCQ six months after ESRD onset (prescribed by a rheumatologist). At the last documented visit, 35/69 patients (51%) had an active HCQ prescription. Patients

Table 1. Factors associated with HCQ use at the last visit post-ESRD*

	HCQ+ last ESRD visit N=35	HCQ- last ESRD visit N=34	p- value
Age at ESRD onset, median (IQR)	33 (26, 46)	46 (29, 53)	0.05
Time from ESRD onset to the last visit, months, median (IQR)	40 (21, 72)	59 (11, 99)	0.3
Women, n(%)	29 (83)	28 (82)	0.95
Arthritis, n(%)	7 (20)	0	0.01
Rash, n(%)	2 (6)	1 (3)	0.61
Oral ulcers, n(%)	1 (3)	0	0.33
Alopecia, n(%)	1 (3)	2 (6)	0.52
Serositis, n(%)	2 (6)	3 (10)	0.59
Cytopenia, n(%)	27 (82)	26 (79)	0.75
Low complement, n(%)	16 (50)	19 (58)	0.54
Elevated dsDNA, n(%)	12 (39)	10 (31)	0.54
Corticosteroid use, n(%)	31 (89)	23 (72)	0.08
Immunosuppressive use, n(%)	25 (71)	14 (42)	0.02
Rheum visit post ESRD at least once, n(%)	29 (85)	20 (59)	0.02

*Symptoms and medications recorded as "ever" after ESRD onset

taking HCQ were younger, more likely to be followed by a rheumatologist, had a higher frequency of documented arthritis, higher frequency of corticosteroid use and immunosuppressive medication use (Table 1). A history of oral ulcers, cytopenias, and elevated levels of dsDNA at any point (either pre or post-ESRD onset) was not significantly associated with HCQ use at the last visit.

Conclusion: HCQ is more likely to be continued among patients with signs of persistently active SLE. HCQ was more likely to be prescribed by a rheumatologist and was associated with the presence of arthritis. Limited systemic evaluation and documentation by the different providers may have resulted in under-reporting of some of the SLE symptoms. However, these findings reflect the "real-world" experience with HCQ use after ESRD in a large tertiary care center.

REFERENCES

- [1] Jung H, et al. *Arthritis and rheumatism*. 2010;62(3):863-8.
- [2] Ruiz-Irastorza G, et al. *Annals of the rheumatic diseases*. 2010;69(1):20-8.
- [3] Broder A, et al. *The Journal of rheumatology*. 2011;38(11):2382-9.
- [4] Bertias GK, et al. *Annals of the rheumatic diseases*. 2012;71(11):1771-82.

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SAT0207

DEVELOPMENT OF QUESTIONNAIRES TO ASSESS HEALTHCARE UTILIZATION AND ACCESS IN PATIENTS WITH PRIMARY SJÖGREN'S SYNDROME AT THE DIAGNOSIS AND DURING THE DISEASE COURSE

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Background: The geographic variation in healthcare spending, utilization and quality, across and within countries is well documented.

Objectives: In this study, we develop and validate a tool to collect comparable information in Europe to establish practice profiles in the diagnosis, management and treatment of patients with Primary Sjögren's Syndrome (pSS).

Methods: Two questionnaires, one to newly diagnosed patients and one for patients at their follow-up visits, have been developed and validated through a pilot survey. The questionnaires aim to assess the pSS patients' experience and satisfaction with the primary care and specialist services received. The questionnaires consist of 30 items and collect patient-reported data on: type and intensity of treatments and services received, costs, patients' satisfaction, patients' overall health, and socio-demographic characteristics. A narrative-based medicine section is also included to explore patients' journey to pSS diagnosis. The questionnaires are administered to a sample of pSS patients attending >20 clinical centers within the European Horizon2020 project "HarmonicSS". Additionally, a short questionnaire is administered to the specialists of the clinical centers to collect data on their organization.

Results: Preliminary results of pilot survey based on questionnaires administered to 164 pSS patients (157 F: 7 M, mean (SD) age = 60 (12.2) years) from 5 clinical centers have been analyzed. The majority of the respondents had a primary or secondary school (59%). Both the total number of specialists involved in the care other than the rheumatologist and the number of treatments received in the last 12 months before the interview varies among patients and across centers (p<0.001). Although, as expected, the most frequently involved specialists were the ophthalmologist (90%) followed by the gynecologist and the dentist. Additionally, patients with lower education have attended on average less specialists than those with a high school or university degree (p<0.001). Findings from the survey to clinicians also show significant geographic variations in the organization of the care to pSS in the participating centres and in the level of integration among different professionals and care settings. On average, 4 professionals (i.e. clinicians and nurses) per centre are involved in care of pSS patients although with significant differences among centre (min=1, max=10) also in the mix of the staff. In 80% of the centres clinicians use written documentation to exchange patients' information, followed by periodic meetings with colleagues (56%) and phone calls with the family doctor (37%). In 54% of the centres the newly diagnosed patients are provided with information pamphlet and

patients health education is performed in 35% of the center through periodic individual meetings.

Conclusion: Preliminary results confirm that the questionnaire is a valid tool to assess and compare patterns of care for pSS patients in terms of access and utilization of treatments and services across and within providers. Once available the questionnaires from all the centres, patient-reported data linked with information from clinical records will allow to measure the patients journey more comprehensively along the care pathway and to identify best practices in terms of the level of perceived quality and the way the care is delivered and, moreover, opportunities for increasing value for patients.

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SAT0208

TEN-YEAR OVERALL SURVIVAL AND STANDARDIZED MORTALITY RATIO IN THE LARGEST SINGLE CENTER COHORT OF PATIENTS WITH PRIMARY SJÖGREN'S ASSOCIATED LYMPHOMAS

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Background: The development of non-Hodgkin's Lymphoma (NHL) in Sjögren's syndrome (SS) contributes to an inferior survival compared to SS patients without lymphoma.

Objectives: To record the long-term outcomes of SS patients with and without NHLs with 10-year survival curves and standardized mortality ratio (SMR) for first time in the literature.

Methods: In order to estimate the effect of NHL development in SS outcome, we expanded the follow-up time of the previously published cohort of SS-associated NHL cases and we retrospectively compared them with age- and sex-matched SS patients without NHL from our center. As outcome end-points, overall and event-free survivals (OS and EFS, respectively) were used. An event was defined as disease relapse or progression, histological transformation or death. Ten-year survival plots and SMR compared to General Greek population were calculated. The impact of rituximab in the outcome of SS associated NHL treated patients was also studied.

Results: From a total of 712 consecutive SS patients who fulfill the 2002 AECG classification criteria for Sjögren's, 77 were diagnosed with NHL. The prevalence of MALT and DLBC lymphoma in the total SS cohort was 7.1% and 1.7% respectively. The median follow-up time from SS diagnosis was 16.67 years (range: 4.00-38.91 years) corresponding to a total of 1283.71 person-years for SS-associated NHL patients and 17.92 years (range: 2.00-34.00 years) with a total of 1380 person-years for SS patients without NHL. The median time from SS to lymphoma diagnosis was 5.5 years (range: 0-38 years) and the median follow-up time after lymphoma diagnosis was 8.2 years (range: 0.1-26.2 years) months. During follow-up, 15 patients from the SS-NHL group died, 11 of whom due to lymphoma-related causes, while only 2 patients died in the control group (one due to advanced ovarian cancer and one due to cardiac arrest) ($p=0.0013$). Patients with SS associated NHL displayed a significantly higher risk of death ($HR=5.95$, 95%CI: 1.66 - 21.38, log-rank test, $p=0.0006$) compared to their counterparts without lymphoma. The corresponding age-adjusted SMR of SS with and without NHLs versus the general Greek population was 7.94 (95%CI 6.82-9.06) and 1.06 (95%CI - 0.06-2.18) respectively. In addition, 18 patients with SS-associated NHL (23.38%) experienced lymphoma relapse or progression and 2 (2.6%) lymphoma transformation; The vast majority of recorded events (27 of 29 events) were observed within the first ten years from NHL diagnosis and DLBCL was associated with the worst outcome; The 10-year EFS% and OS% for DLBC was 22.22% and 48.61% respectively while for MALT were 68.15% and 82.03%, respectively. Interestingly, the introduction of rituximab in the anti-lymphoma chemotherapeutic regimens didn't offer any long-term survival benefit.

Conclusion: Herein, we present the longest, to our knowledge, follow-up time of patients with SS-associated NHL; The majority of events that determine the morbidity and mortality of SS-NHL patients have already occurred within the first ten years from NHL diagnosis. In individuals with

SS, the evolution of NHL was found to have a detrimental effect in patients' survival. Among them, DLBCL patients experienced the worst outcome.

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SAT0209

A SIMPLIFIED APPROACH FOR SLE PATIENTS TO REPORT DISEASE ACTIVITY USING A REVISED VERSION OF THE SWEDISH SYSTEMIC LUPUS ACTIVITY QUESTIONNAIRE

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Background: The Systemic Lupus Activity Questionnaire (SLAQ) is a validated questionnaire, which captures patients' assessments of SLE-related symptoms and disease activity (1). However, it is extensive and in a recent study we found that some questions were difficult to answer, added little information, or had poor correlation with physicians' assessments (2). Thus, herein we revised the Swedish version of the questionnaire (SWE-SLAQr), building on previous results and we also asked patients for input. Our aim was to get an improved and shorter version, to support clinical work and online registries. The original SLAQ includes 26 items, while SWE-SLAQr includes 20 items.

Objectives: We compared patients' assessments of SLE disease activity, as reported in the SWE-SLAQr, with physicians' assessments using SLE activity measure (SLAM) and SLE disease activity index (SLEDAI-2K). In addition, we evaluated the performance of the symptom items of SWE-SLAQr as compared to the corresponding items in SLAM.

Methods: Patients filled out SWE-SLAQr prior to physicians' assessments. Correlations between SWE-SLAQr-total, sub-scales (Symptom score, Patients global) and SLAM-excluding the 7 laboratory items (SLAM-nolab), SLAM and SLEDAI-2K as well as between the corresponding items in SLAQ and SLAM, were evaluated using Spearman's ρ .

Results: We included 101 patients, 85% women, median age 43 (IQR 22) years, disease duration 14 (IQR 15) years. Patients reported more symptoms than recorded by doctors. Correlations between patients' and physicians' assessments were for SLAM-nolab: SWE-SLAQr total, $\rho=0.674$, Symptom score, $\rho=0.670$, and Patients global, $\rho=0.667$, as expected the correlations were lower for SLAM: SWE-SLAQr total, $\rho=0.472$, Symptom score, $\rho=0.467$, and Patients global, $\rho=0.501$. No correlations were found between patients' and physicians' assessments when using SLEDAI-2K ($p<0.09$ for all). Of symptom items fatigue ($\rho=0.741$), alopecia ($\rho=0.695$) and weight loss (0.517) showed highest degree of correlation. Notably, symptoms of dyspnea/pleuritic chest pain had no correlation between patients' and physicians' assessments ($\rho=0.152$, $p=0.130$).

Conclusion: We conclude that SWE-SLAQr performed equally well as SLAQ (2), demonstrating that it can be used to monitor disease activity. We encourage further use of SWE-SLAQr and recommend its implementation in clinical care, we believe it is especially well suited to support digital and telephone contacts. However further attention is needed to evaluate the discrepancy between physicians' and patients' evaluation of thoracic pain/symptoms.

Table. Characteristics of participants

	Median	IQR
SWE-SLAQr total (0-37)	8	3.5-13
Symptom score (0-19)	9	4-13.5
Patients global (0-10)	4	1-7
SLAM	4	2-8
SLAM nolab	3	1-6
SLEDAI-2K	2	2-5.5