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