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.

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SAT0206

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

Maria Salgado Guerrero¹, Alejandra Londono Jimenez², Chrisanna Dobrowsky², Shudan Wang², Anna R. Broder². ¹Jacobi Medical Center/Albert Einstein College of Medicine, Internal Medicine, Bronx, NY, United States of America; ²Montefiore Medical Center/Albert Einstein College of Medicine, Rheumatology, Bronx, NY, United States of America

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.

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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

Chiara Seghieri¹, Chiara Baldini², Themis Exarchos³, Luca Quartuccio⁴, Elena Bartoloni Bocchi⁵, Roberta Priori⁶, Francesco Carubbi⁷, Francesco Ferro², Saviana Gandolfo⁴, Stefano Bombardieri², Salvatore De Vita⁴, Athanasios Tzioufas⁸. ¹Sant'Anna, Pisa, Italy; ²University of Pisa, Pisa, Italy; ³University of Ioannina, Ioannina, Greece; ⁴University of Udine, Udine, Italy; ⁵University of Perugia, Perugia, Italy; ⁶University of Roma, Roma, Italy; ⁷University of L'Aquila, L'Aquila, Italy; ⁸University of Athens, Athens, Greece

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