- The belief that HCQ is “Very important” (12.9% “low”) rather than “important” (22.1% “low”) or “not important / useless” (33.1% “low”).
- Taking many different medications (9.8% “low”) for Patients indicating more than 7 medications vs 19.6% for those listing 3 or less.
- Childhood onset of the SLE was associated with a lower adherence (30.0% “low” vs. 17.4% for later onset SLE (p<.001).
- 658 patients (29.6%) reporting having experienced side effects. 42.6% of them stopped taking HCQ (patient led 161, doctor led 110, unclear 9). Amongst those continuing HCQ despite experiencing side effects, the proportion of non adherent patients increased to 24.7%, compared to 15.2% in the group of patients that have not experienced side effects (p=.0001).
- 232 patients who talked with their Doctor and felt listened to appear to adhere better (22.0% low adherence) is only directional (p<0.15).
- 523 patients have used HCQ in the past. 206 (39.4%) consider the decision to stop HCQ as doctor initiated, 272 (52.0%) as patient initiated, and 36 (6.9%) as a joint decision.
- When stopping was patient initiated, 59.9% was due to experiencing a significant side effect attributed by the patient to HCQ, 6.7% due to concern of a potential side effect, 11.2% “tested” stopping and noticed no difference, 10.0% were not convinced that it worked, 8.2% felt their lupus was less active, 2.6% wanted to reduce pill consumption. (Side effects attributed to HCQ may relate to age, disease activity and other factors).
- Conclusion: Doctors can help HCQ adherence by boosting patient’s confidence in the importance of HCQ. Better patient education may contribute to avoid up to 40% of patient initiated decision to stop HCQ treatment.

References:

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AB0373 TREATMENT OF SLE WITH THE IMMUNOPROTEASOME INHIBITOR KZR-616: RESULTS FROM THE FIRST 4 COHORTS OF THE MISSION STUDY, AN OPEN-LABEL PHASE 1B DOSE ESCALATION TRIAL

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Background: Chronic inflammatory rheumatic diseases are often associated with a negative effect on pregnancy outcome. Most obstetrical complications are placenta-mediated such as preterm delivery and growth restrictions. In women with Sjögren syndrome, data on placenta-mediated complications are scarce and conflicting (1,2).

Objectives: To analyse neonatal outcome in women with Sjögren syndrome with focus on preterm delivery and growth restriction.

Methods: We retrospectively analysed 23 pregnancies of 16 patients with Sjögren syndrome that were followed at our centre with regard to pregnancy outcome, medication and disease characteristics. Small for gestational age was defined as birthweight percentile <10th. Preterm delivery was defined as delivery before 37, early term as delivery between 37:39 and term as delivery between 39:42 weeks of gestation.

Results: Of 23 pregnancies, one ended in a miscarriage and 22 resulted in live births including one set of twins. Treatment used during pregnancy was hydroxychloroquine (20 pregnancies), prednisone (8), azathioprine (5) and cyclosporine (2). Concomitant treatment with low-dose aspirin was used in 9 pregnancies.

Of the 22 live births, 17 were born at early term and 5 at term. There were no preterm deliveries. Median birth weight was 2820g (range 2095-3845g). Nine newborns (40.9%) were small for gestational age (SGA), Maternal treatment during these pregnancies was hydroxychloroquine in all cases and additional low-dose aspirin in three cases. Elevated CRP levels during pregnancy were found in 57% of the cases with SGA outcome. Only one woman with an SGA infant had positive anti-phospholipid antibodies.

Regarding delivery mode, most patients had caesarean sections.

Conclusion: In our cohort of women with Sjögren syndrome the prevalence of small for gestational age infants was high despite maternal treatment with hydroxychloroquine. Inflammatory markers could help to identify the patients at risk for placental insufficiency, yet prospective studies of larger cohorts are needed.

References:

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LUPUS LOW DISEASE ACTIVITY STATE AND MAINTAINING DRUG THERAPY: A RETROSPECTIVE INVESTIGATION

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Background: Systemic lupus erythematosus (SLE) is a chronic autoimmune multisystemic disease, that can begin with a wide range of clinical manifestations, and requires immunosuppressive therapies (1). A treat-to-target strategy leads to a high rate of clinical remission among patients (2). Several "remission" definitions have been provided in the last years and Lupus Low Disease Activity State (LLDAS) seems one of the best tools to evaluate it in clinical practice (3).

Objectives: To evaluate the prevalence of SLE signs and symptoms at onset and the drugs used to induce and maintain the clinical remission, evaluated by LLDAS, in a real-life cohort of SLE patients.

Methods: Thirty female SLE patients (mean age 52±15 years; mean age at disease onset 34±16 years, mean disease duration 18±13 years) in clinical remission have been enrolled (EULAR/ACR 2019 criteria) (4). Remission was defined by LLDAS (SLEDAI-2K ≤ 4 and no activity in major organ systems, no hemolytic anemia; no new features of activity compared with disease onset) (3-5).

Results: Mucocutaneous involvement (57%), arthritis (30%), serositis (30%), nephritis (27%), leucopenia (23%), thrombocytopenia (20%), hemolytic anemia (13%), antiphospholipid syndrome manifestations (16%), neuro-psychiatric lupus symptoms (6%) were present in various combinations at disease onset. Baseline mean SLEDAI-2K was 10.5±2.5. Patients were treated with different dosages of glucocorticoids (100%), hydroxychloroquine (HCO, 73%), cyclofosfamide (20%), mycophenolate mofetil (MMF, 13%), azathioprine (AZA, 13%), methotrexate (MTX, 13%), cyclosporine A (CSA, 6%), rituximab (3%), abatacept (ABA, 3%). Glucocorticoids were prescribed together with a DMARD 30%. Prednisone ≤ 5 mg/day and/or MMF ≤ 7.5 mg/da and/or HCQ ≤ 400 mg/day and/or CSA ≤ 200 mg/day and/or MTX ≤ 10 mg/week and/or MMF ≤ 2.5 g/day and/or AZA ≤ 100 mg/day. In particular, only prednisone 7%, only HCQ 3%, prednisone + HCQ 53%, prednisone + single DMARD (different from HCO) 7%, prednisone + HCQ + DMARDs 30%.

Conclusion: After reaching the clinical remission by a treat to target strategy, the administration of low dose of prednisone and HCO in the majority of SLE patients (63%) seems useful to prevent new SLE flares. The retrospective design and the absence of a control group of patients with active disease limit this study.