management. Herein, we explored patient and physician descriptions of lupus flares.

Methods We conducted a qualitative descriptive study using in-depth interviews with a purposeful sample of SLE patients (1997 ACR or SLICC criteria) selected for age, race, sex and nephritis; we also interviewed a range of rheumatologists. Interviews were audio-recorded and transcribed. The data were analyzed using applied thematic analysis by a team of qualitative analysts and rheumatologists.

Results We interviewed 42 SLE patients (mean age 45, 93% female, 52% Black, 52% college educated, 15 mean years of disease, 33% historical nephritis). The majority of patients described flare symptoms as joint pain, fatigue, and rashes. Other common symptoms included swelling, myalgias, mood disturbance and flu-like symptoms. Several patients noted brain fog and weakness as flare symptoms. One patient included nephritis and one noted lab abnormalities as signs of flare. According to patients, the majority of flares lasted a matter of days although some quantified flare length as weeks or months. Patients considered stress as the most common trigger.

Thirteen rheumatologists (mean age 54, 53% Female, 61% non-Hispanic White, mean 25 practice years) from 10 academic and 3 community centers were interviewed. All rheumatologists cared for SLE patients; half had a SLE clinical focus and 75% conducted SLE research. The majority of rheumatologists defined flare as an increase in disease activity, with more than half requiring objective findings while a few incorporated a change in therapy. Around half of rheumatologists included fatigue, pain or patient reported symptoms as part of a lupus flare; however, another 2 specifically excluded patient-reported symptoms. A few rheumatologists acknowledged patient and physician discordant views.

Conclusion Together, these data suggest that patients and physicians have different views of flares. Patients view flares as short-lived periods of fatigue, myalgia and arthralgia often prompted by stress. Providers view flares as an objective increase in lupus inflammation requiring immunosuppression. Appreciating this discrepancy is important since patients could misinterpret their rheumatologist's assessment. Moreover, discounting the patient experience could impair the patient-physician relationship with implications for adherence and outcomes. Further study is needed to understand the immunologic basis of patient flares and determine the best approach to incorporate the patient perspective into clinical assessments and management.

1114 TRAJECTORY OF DAMAGE ACCRUAL IN SYSTEMIC LUPUS ERYTHEMATOSUS BASED ON ETHNICITY, SOCIOECONOMIC FACTORS AND COMORBIDITIES

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Background The Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) is associated with increased healthcare cost and mortality. We compared the trajectory of total and individual damage items of the SLICC/ACR DI in African-American vs Caucasian ethnicities in a large prospective SLE cohort. We calculated the attributable risk of comorbidities and socioeconomic factors.

Methods Poisson regression was used to calculate the rate of damage per year for each organ. Cox regression modeling was used to determine the association between time to the individual damage item and ethnicity. Pooled logistic regression models of prospective data were used to calculate the population attributable risk (PAR) for each damage organ.

Results We included 2,436 patients: 43% African-American, 57% Caucasian, and 92% female. There was a linear relationship between time since diagnosis and mean SLICC/ACR DI score, with no plateau. Compared to Caucasians, African-Americans had a faster total, renal, pulmonary, and skin damage accrual rate. Hypertension contributed to 30% of total damage, 70% of renal and 40% of cardiovascular damage. The three socioeconomic measures (education, income, and insurance) accounted for only about 10% of any organ damage and contributed approximately equally to total damage.

Conclusions The linear increase in damage in both ethnicities over time is of particular concern. Ethnicity and hypertension are both important contributors to organ damage in SLE, but socioeconomic factors play a lesser role.

1115 THE TYPE 1 & 2 SLE MODEL: THE PERSPECTIVE OF PATIENTS AND RHEUMATOLOGISTS

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Background We have proposed a new model that divides SLE manifestations into Type 1 (objective signs of inflammation) and Type 2 (generalized pain and fatigue not clearly due to inflammation). We sought the opinions of patients and rheumatologists to assess the model's face-validity based on their experience living with and/or managing SLE.

Methods Recorded interviews were conducted and analyzed with 42 adults with SLE and 13 rheumatologists. Patients were purposefully recruited to reflect a spectrum of active and inactive Type 1 and 2 SLE. Clinicians were intentionally selected to include leading experts in SLE and community rheumatologists.

Results Most patients approved of the Type 1 & 2 SLE model and several patients said it was 'spot on.' Almost all patients accurately characterized their experience with SLE has having more Type 1, 2, or Mixed symptoms based on their clinical history. One patient with predominantly Type 2 symptoms felt that she had only Type 1 disease as she believed inflammation caused her chronic pain and fatigue. Two patients had difficulty separating Type 1 and 2 symptoms, one having only experienced these together and the other feeling the categorization was 'limiting and binary.' Many patients discussed the connection between their Type 1 & 2 symptoms.

The majority of rheumatologists approved of the model. Many reported using a similar approach and found the addition of specific labels helpful. They felt it could be useful for counseling patients on symptom etiology and the expected impact of medications. Some felt applying the model in patient care could help them determine their therapeutic approach. Several rheumatologists emphasized that Type 2

symptoms could only be found in patients with an established diagnosis of SLE. In addition, a few rheumatologists were concerned about labeling Type 2 symptoms as 'SLE' since they attributed these symptoms to co-morbid conditions. Conversely, two providers noted that Type 2 symptoms could sometimes be part of Type 1 SLE activity.

Conclusion The Type 1 & 2 SLE model was well accepted by both patients and rheumatologists and considered as a useful approach to identifying and treating SLE manifestations. The concern that SLE could be mis-diagnosed in patients with only Type 2 symptoms indicates the importance of limiting the use of this model to patients meeting classification criteria for SLE. Many patients and several physicians suggested that the connection between Type 1 and 2 SLE may reflect an inflammation-driven subset of Type 2 symptoms.

1116 LONG-TERM OCULAR SAFETY OF HYDROXYCHLOROQUINE IN PATIENTS WITH CHILDHOOD-ONSET SLE (CSLE) FOLLOWED INTO ADULTHOOD

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Background In recent years there has been increasing concerns about the long-term ocular toxicity of hydroxychloroquine which has resulted in increased vigilance of the use of a maximum of 5 mg/kg/day. The aim of this study was to determine the long-term ocular safety of the use of hydroxychloroquine in patients with cSLE.

Methods The SLE Clinic database at SickKids hospital was searched for all patients followed since its inception in 1985 diagnosed and followed who were treated with hydroxychloroquine. Follow-up data was obtained into adulthood by reviewing the records of patients following transfer to care at an adult SLE clinic. While treated at SickKids all patients were treated with hydroxychloroquine at a dose 5.5-6 mg/kg/day (maximum 400 mg/day).

However, following the recent recommendations for lower dosing of hydroxychloroquine, some of the patients had their dose lowered while followed in adulthood. All patients had regular hydroxychloroquine ophthalmologic follow-up at recommended intervals of 6-12 months. Exclusion criteria were: cSLE not diagnosed at SickKids Hospital, <2 follow visits, no documentation of ophthalmology follow-up or no documentation of hydroxychloroquine dose. This study was approved at local ethics boards at all participating centers.

Results A total of 718 patients with cSLE diagnosed until the end of 2019 were found in the SickKids Clinic database. 15 were not diagnosed with cSLE at SickKids or had <2 follow-up visits; 4 were eliminated as the hydroxychloroquine was stopped within one month for systemic side-effects. The study cohort there consisted of 699 patients who were followed for a total of 5815.5 person years. The mean follow-up time was 8.33 years (SD 6.15 years) (minimum 0.2 years and maximum of 35.9 years). 456/699 (65%) had $\geq$ 5year follow-up, 218 (31%) $\geq$ 10 years; and 41(6%) $\geq$ 20 years. During the follow-up time one patient stopped hydroxychloroquine for deposition in the retina without visual changes. A second patient had hydroxychloroquine stopped based on an optometrist's examination but when reviewed by an ophthalmologist, no retinal changes were noted.

Conclusions In this long-term follow-up study of patients with cSLE treated hydroxychloroquine at a dose of 5.5-6.0 mg/kg/day (maximum 400 mg/day) there was no evidence of visual changes after long-term follow-up of 5815.5 person years (patients followed for up to 35.9 years). We suggest that, unlike the potential for ocular toxicity of hydroxychloroquine found it studies of adult at doses > 5mg/kg/day, patients with cSLE can be treated with 6 mg/kg/day prior to transfer to adult care.

1117 SLE PHENOTYPES FORMED FROM MACHINE LEARNING AND THEIR ASSOCIATIONS WITH COGNITIVE IMPAIRMENT

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Background Cognitive impairment (CI) in SLE is highly prevalent. Several factors are associated with CI: depression, pain, fatigue, medications, as well as more specific SLE factors such as disease damage, and autoantibodies. We aimed to phenotype CI in SLE using machine learning techniques to enable personalised targeted treatments.

Methods SLE patients aged 18-65 years attending a single completed the ACR Neuropsychological Battery (ACR-NB) cognitive assessment. Z-scores on all 19 tests of ACR-NB. ACR-NB tests were reduced using principal component analysis (PCA) to generate a factor score (CI Factor Score).

Demographic, clinical data, and patient reported outcomes including, SF-36, LupusQoL, the PDQ-20 (perceived cognitive deficits), Beck Depression Inventory-II, Beck Anxiety Inventory, and the fatigue severity scale (FSS) were analysed using similarity network fusion (SNF) to identify patient subtypes. Differences between the SNF identified subtypes were evaluated using Kruskal-Wallis tests and chi-square tests.

Results Of 301 patients, 89% were women, mean age and disease duration at study visit 40.9 ± 12.1 years. The CI Factor score accounted for 28.8% of the variance and was associated predominantly with executive function and verbal memory. The SNF defined **three subtypes** (1, 2 and 3 with 60, 112, and 129 patients respectively) with distinct patterns in health-related quality of life (HRQoL), depression, anxiety, fatigue, fibromyalgia, medication usage, and damage. The CI Factor Score was significantly different between the subtypes. Examining specific cognitive domains revealed the most significant differences in the language processing and executive function tests. Subtype 3 performed worst on the majority of cognitive domains). Further exploration revealed statistical differences with depression, anxiety, fatigue, and fibromyalgia between the subtypes (figure 1). Differences were also found relating to organ involvement within the last ten years and damage within specific organs. No differences were found for SLE disease activity. Subtype 3 had higher levels of all conditions and