with higher scores reflecting better HR-QoL. We used the 'mclust 5.4.9' model-based clustering package in R V4.0.4 to identify latent profiles (LP) of patients who experienced distinct HR-QoL patterns. Variances were equated and covariances fixed to zero. Missing values were imputed using methodology suggested by the SF-36 manual. Number of comorbidities included osteoarthritis, chronic kidney disease, ischaemic heart disease, cancer, diabetes, reflux disease, chronic liver disease, obstructive airway disease or interstitial lung disease, thyroid disease, stroke, vitiligo, Addison's disease and atrial fibrillation. Multivariable ordinal logistic regression was used to determine patient-level characteristics associated with membership in the HR-QoL subgroups. Models were adjusted for ethnicity, sicca, fibromyalgia, and number of comorbidities.

Results 309 patients with a variety of CTDs recruited into LEAP completed the SF-36 questionnaire, (280 [90.6%] women, mean [SD] age 48.9 [12.9] years). There were 115 (37.2%) patients with lupus, 72 (23.3%) undifferentiated CTD, 56 (18.1%) primary Sjögren's syndrome and 66 (21.4%) patients with systemic sclerosis, idiopathic inflammatory myopathy or an overlap syndrome (SSc-IIM). Three LP were identified with poor (n=89), average (n=190) and excellent (n=30) HR-QoL (figure 1). In multivariable models, LP were not associated with diagnostic grouping (Sjogren's: OR 0.97 [95% CI 0.46–2.06]; undifferentiated CTD: OR 1.05 [95% CI 0.57–1.92]; SSc-IIM: OR 0.89 [95% CI 0.48–1.68]). Black ethnicity (OR 0.26 [95% CI 0.10–0.70]) or Asian ethnicity (OR 0.41 [95% CI 0.21–0.81]), concomitant fibromyalgia (OR 0.44 [95% CI 0.22–0.86]), sicca phenomenon (OR 0.56 [95% CI 0.35–0.91]) and multi-morbidity (OR 0.80 [95% CI 0.63–1.00]) were associated with membership of a lower HR-QoL LP.

Conclusion CTD patients can be clustered into distinct HR-QoL subgroups agnostic of their clinical diagnosis which may have meaningful implications in practice for stratifying therapy. This study highlights that sicca syndrome, ethnicity, fibromyalgia and multi-morbidity are key areas to focus on in improving HR-QoL in patients with a CTD, irrespective of clinical diagnosis or antibody profile.

PO.7.143 VALUE OF FATIGUE: PATIENTS VS. PHYSICIANS – TIME TRADE-OFF APPROACH RESULTS FROM A PATIENT SURVEY

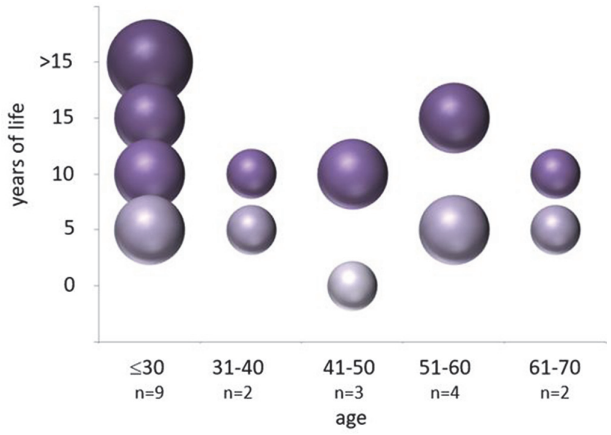
C Duesing*, M Schneider, G Chehab. *Policlinic and Hiller Research Unit of Rheumatology, UKD, Heinrich-Heine-University Duesseldorf ~ Germany*

10.1136/lupus-2022-elm2022.163

Purpose Fatigue is a very common symptom in SLE patients and often held responsible for their reduced quality of life. With this survey, we wanted to examine the degree of suffering in SLE patients with fatigue and determine, whether they would trade in years in order to live without fatigue or if they would trade in fatigue for other disease manifestations (skin, joints or kidney). We also looked at the number of patients, who were regularly asked about fatigue by their treating physician.

Methods Our patient survey took place during a meeting with patients from the German SLE self help community on World Lupus Day, May 10th 2019 in Düsseldorf, Germany. We used Edivote®, which is an anonymous, audience response system working with PowerPoint® for our survey. Patients' demographics (age, gender and disease duration) were documented separately. We asked if patients had been questioned by their treating physicians about fatigue (1: always, 2: sometimes, 3: never), how many years of life they would sacrifice in order to live without fatigue (0, 5, 10, 15, >15 years, respectively) and who would trade in fatigue for another disease manifestation (skin, joints or kidney).

Results 26 patients (25 female) agreed to take part in our survey and completely or in part responded to the questions asked. Most patients were ≤50 years old (n=16, 61.5%). Most patients had a disease duration of >5 years (6–10 years: n=5; >10 years: n=16). Six patients were regularly asked about fatigue, four patients were sometimes asked about fatigue and eight patients had never been asked about fatigue. The results of the time trade-off question are shown in figure 1, sorted by patients' age. In our cohort, five patients were willing to trade in fatigue for a skin manifestation (consistent redness on exposed skin). One patient was willing to trade in fatigue for a kidney manifestation (50% reduction of kidney function, accompanied by edema and fluid restriction). Twelve patients did not want to trade in fatigue for one of the mentioned disease manifestations.



Abstract PO.7.143 Figure 1 Results from our time trade-off survey, sorted by patients, age; n=20, absolute numbers; (Size of circles represents 1 patient [small], 2 patients [medium] and 3 patients [large])

Conclusion 42% of responding patients in our cohort (n=19) had never been asked about fatigue by their treating physicians. To our surprise, almost all patients were willing to trade in at least 5 years and more for a life without fatigue. This result underlines patients' degree of suffering and should raise more awareness for SLE patients living with fatigue. Our results clearly indicate the discordant assessment of the importance of fatigue by patients and physicians. Although our cohort is small and relatively young, even some patients between the age of 61 and 70 were willing to trade in up to 10 years for a life without fatigue. Future research must be conducted to better understand fatigue in SLE patients and to develop appropriate treatment strategies. Our results with respect to time trade-offs should be validated in a larger cohort.

Lupus Sci Med: first published as 10.1136/lupus-2022-elm2022.163 on 27 September 2022. Downloaded from http://lupus.bmj.com/ on April 19, 2024 by guest. Protected by copyright.