Abstract 13 Table 1 Multiple linear regression analysis for the HRQOL

Variables	Co-efficient	95%CI Lower	95%CI Upper	Standardized β
Intercept	**92. 52**			
GC (mg daily)	**-0. 88**	-1. 45	-0. 31	-0. 23
Age (years old)	**-0. 07**	-0. 29	0. 15	-0. 05
Sex male [reference]	**-13. 62**	-21. 35	-5. 90	-0. 25
GC-related SDI >1 SDI=0 [reference]	**-8. 14**	-14. 56	-1. 72	-0. 20
GC-unrelated SDI >1 SDI=0 [reference]	**-5. 04**	-10. 92	0. 83	-0. 12

HRQOL; Health-Related Quality of Life, SLEDAI; Systemic Lupus Erythematosus Disease Activity Index, 95% CI; 95% confidence interval, GC; Glucocorticoid (prednisolone-equivalent dose), SDI; Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index.

and the GC-related damage has a greater impact on HRQOL from standardized -coefficients. Multiple imputation was performed for missing data.

Results Of the 188 enrolled patients, 84% were female and the median age was 44 (interquartile range [IQR] 35–55) years. The median SLEDAI was 4 (IQR 2–8) and the median of daily prednisolone dosage was 5 (IQR 4–9) mg. The median HRQOL score was 70 (IQR 53–84). HRQOL was significantly associated with the daily dose of prednisolone (=−0.50 [95% confidence interval (CI) −0.99 to −0.02]), SDI 1 (=−8.2 [95%CI −14.0 to −2.4]) and female (=−11.8 [95%CI −19.8 to −3.9]). Multiple linear regression analysis showed that the daily prednisolone dose was significantly associated with HRQOL (=−0.88 [95%CI −1.45 to −0.31]). The current daily dose of GC had a greater influence on HRQOL than the GC-related damage (standardized=−0.23 vs standardized=−0.20). After multiple imputation of missing values, our findings did not substantially change (=−0.66 [95%CI −1.14 to −0.17]).

Conclusions The daily dose of GC was associated with HRQOL among SLE patients rather than the GC-related damage. These findings may help to understand the effects of GC treatment on HRQOL.

Funding Source(s): None

14 NOT HAVING THE REAL SUPPORT THAT WE NEED: PATIENTS EXPERIENCES WITH AMBIGUITY OF SYSTEMIC LUPUS ERYTHEMATOSUS AND EROSION OF SOCIAL SUPPORT

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Background A hallmark of SLE is the paroxysmal disease course with symptoms fluctuating unpredictably both across different individuals and within individual cases. Importantly, the patient-specific experience of living with SLE is underreported, particularly when studying factors associated with health-related quality of life (HRQOL). Recent work has suggested that biomedical interventions are only partially predictive of HRQOL measures. The patient specific experience studied using qualitative methods is a necessary initial step to uncover additional root causes of poor HRQOL in SLE populations as patient experiences add richness and depth to a topic of inquiry not possible through quantitative methods.

Methods Consented adult patients with American College of Rheumatology- or Systemic Lupus International Collaborating Clinics-classified SLE were recruited for this study during their scheduled clinic visits. Ten semi-structured interviews were conducted across six participants. Interviews were audio recorded, transcribed, and analyzed using an iterative process where all data were first grouped based on the major questions of the study and then coded using an open coding scheme, allowing for identification of key issues based on patient experiences. Findings were presented to an interactive public forum with SLE patients, family members and friends of individuals with SLE, and health care professionals and assessed for accuracy and credibility.

Results Four major factors that influence HRQOL emerged from the interviews: 1) ambiguity, inconsistency, and lack of symptom predictability due to SLE disease courses, 2) poor communication with family/friends/partners, and poor bi-directional communication between health care providers and patients (informational support), 3) lack of validation for patients experiences (appraisal support), and 4) problematic aspects of social support including negative support and patients inability to reciprocate support due to role changes. Data also indicate a reciprocal association between appraisal and informational sources of support.

Conclusions Findings indicate that inadequate appraisal and informational support from informal and formal sources and ambiguity are particularly salient factors influencing HRQOL

among SLE patients. Further investigation is needed to fully elucidate associations between biological (unpredictable of SLE symptoms), social (informational and appraisal sources of social support), and community level (public awareness campaigns) factors influencing disease. Findings also point to the necessity of integrating community organizations, physicians, and friends and family of patients with SLE into capacity building interventions aimed at improving HRQOL.

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15 FREQUENCY OF HYDROXYCHLOROQUINE RETINOPATHY IN THE HOPKINS LUPUS COHORT

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Background The Kaiser-Permanente study projected hydroxychloroquine (HCQ) retinopathy rates of 40% after 20 years of use. We have prospectively followed SLE patients in the Hopkins lupus cohort to compare.

Methods Patients in the Hopkins cohort are seen quarterly for assessment of disease activity and lupus complications. Yearly ophthalmology examinations are requested. Patients, if insurance allows, are referred to the Wilmer Retina group. Four tests are performed: OCT, ERG, MP-1 and FAF.

Results Patients had a variety of retinal testing done, with optical coherence testing most frequent. Table 1 shows the concordance of a test abnormality with the retina expert opinion.

The concordance of the test abnormality with the retina expert opinion showed the following sensitivity and specificity, respectively: OCT 93%, 84%; ERG 100%, 51%; MP1 100%, 70%; and FAF 83%, 76%.

The frequency of retinopathy increased with years of HCQ use [number of retinopathies per total patients (percent frequency)]: 5 years or less, 1/103 (0.97%); 6–10 years, 2/109 (1.83%); 11–15 years, 3/91 (3.30%); 16–20 years, 11/96 (11.46%); and 21 or more years, 6/75 (8.00%).

Conclusions In agreement with the American Academy of Ophthalmology, OCT appears to be the optimum test for yearly monitoring. The frequency of retinopathy was much lower in our prospective study than estimated by the Kaiser-Permanente study. Our data also show the need for ophthalmologists with retinopathy expertise to interpret retina testing, as screening tests are frequently abnormal due to causes other than HCQ retinopathy. Stopping HCQ based on an abnormal test without confirmation from a retinopathy expert could needlessly deprive an SLE patient of an important medication.

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Abstract 15 Table 1 Performance of retinal imaging modalities relative to expert diagnosis

Test	Retinopathy N (%)	No Retinopathy N (%)
Ocular Coherence Tomography (OCT)		
Abnormal	25 (93%)	133 (16%)
Normal	2 (7%)	721 (84%)
Total	27	854
Electroretinogram (ERG)		
Abnormal	15 (100%)	195 (49%)
Normal	0 (0%)	201 (51%)
Total	15	396
Microperimetry (MP1)		
Abnormal	17 (100%)	144 (30%)
Normal	0 (0%)	331 (70%)
Total	17	475
Fundal Autoflourescence (FAF)		
Abnormal	19 (83%)	165 (24%)
Normal	4 (17%)	536 (76%)
Total	23	701

16 HYDROXYCHLOROQUINE BLOOD LEVELS PREDICT RETINOPATHY IN SLE

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Background Hydroxychloroquine (HCQ) retinopathy after 10 years or more of use is more frequent than previously appreciated. This led to new ophthalmology guidelines that

Abstract 16 Table 1 Risk of HCQ retinal toxicity (univariate)

	No n (%)	Yes n (%)	p	P for Trend
Characteristic				
Sex			0.1029	
Female	475 (96.2)	19 (3.8)		
Male	39 (90.7)	4 (9.3)		
Ethnicity			0.3804	
White	238 (94.4)	14 (5.6)		
Black	215 (96.4)	8 (3.6)		
Other	61 (98.4)	1 (1.6)		
Age			<0.0001	<0.0001
<45	215 (99.5)	1 (0.5)		
45–59	175 (95.6)	8 (4.4)		
60+	124 (89.9)	14 (10.1)		
HCQ max			0.0340	0.0143
1 (0 to 1182)	161 (98.8)	2 (1.2)		
2 (1183 to 1752)	157 (95.2)	8 (4.8)		
3 (1753 to 6281)	153 (93.3)	11 (6.7)		
HCQ duration			0.0006	0.0002
1 (0 to 8 years)	158 (98.8)	2 (1.2)		
2 (9 to 15 years)	139 (97.2)	4 (2.8)		
3 (16 to 48 years)	154 (90.1)	17 (9.9)		
BMI			0.1701	0.0160
<20	50 (98.0)	1 (2.0)		
20–25	171 (97.7)	4 (2.3)		
25–30	159 (95.2)	8 (4.8)		
30–35	76 (95.0)	4 (5.0)		
35+	58 (90.6)	6 (9.4)		
HTN Ever			0.0020	
Yes	276 (93.2)	20 (6.8)		
No	238 (98.8)	3 (1.2)		