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# SYMPTOM IMPACT AND UNMET NEED IN SYSTEMIC/CUTANEOUS LUPUS ERYTHEMATOSUS: RESULTS FROM A PATIENT-CENTRED STUDY SET IN A SOCIAL MEDIA COMMUNITY

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**Background and aims** Patient perspectives in lupus are poorly understood; better understanding by manufacturers and regulatory agencies is necessary for patient-focused drug development. This study's aims were to obtain the patient view of symptom impact and unmet need among those with systemic lupus erythematosus (SLE), including those with skin manifestations.

**Methods** The study population consisted of consenting, adult members of an English-language, lupus-focused social media community. A 23-item on-line questionnaire including an embedded consent form was deployed. Both structured response category and open-ended questions were included to allow for emerging concepts. An Institutional Review Board reviewed this study and gave an 'exempt' determination.

**Results** Respondents (n=569) were majority female (97%), aged 40–59 (66%) and using medications consistent with SLE (e.g., 69% hydroxychloroquine). Fatigue was the most frequently-reported (90%) symptom of great impact, followed by joint pain (74%) and other pain (57%). In open-ended responses, the most frequently-mentioned theme was impact on normal/daily life activities (Figure 1).

Among those reporting ever having skin symptoms (n=404), light sensitivity was the most frequently-reported skin symptom of great impact (66%). This varied when

comparing African Americans (n=77) and whites (n=245), where hair loss (56%) and light sensitivity (68%) were most frequent, respectively. In open-ended responses about how skin symptoms affect life, activity limitations due to sun/light/heat sensitivity were the most frequently-mentioned themes (Figure 2).

Finally, considering novel treatment preferences, desire for pain/fatigue relief were most commonly cited (about one-third each).

**Conclusions** This large, non-clinical study suggests several outcomes of meaningful importance to SLE patients, including those with skin symptoms.

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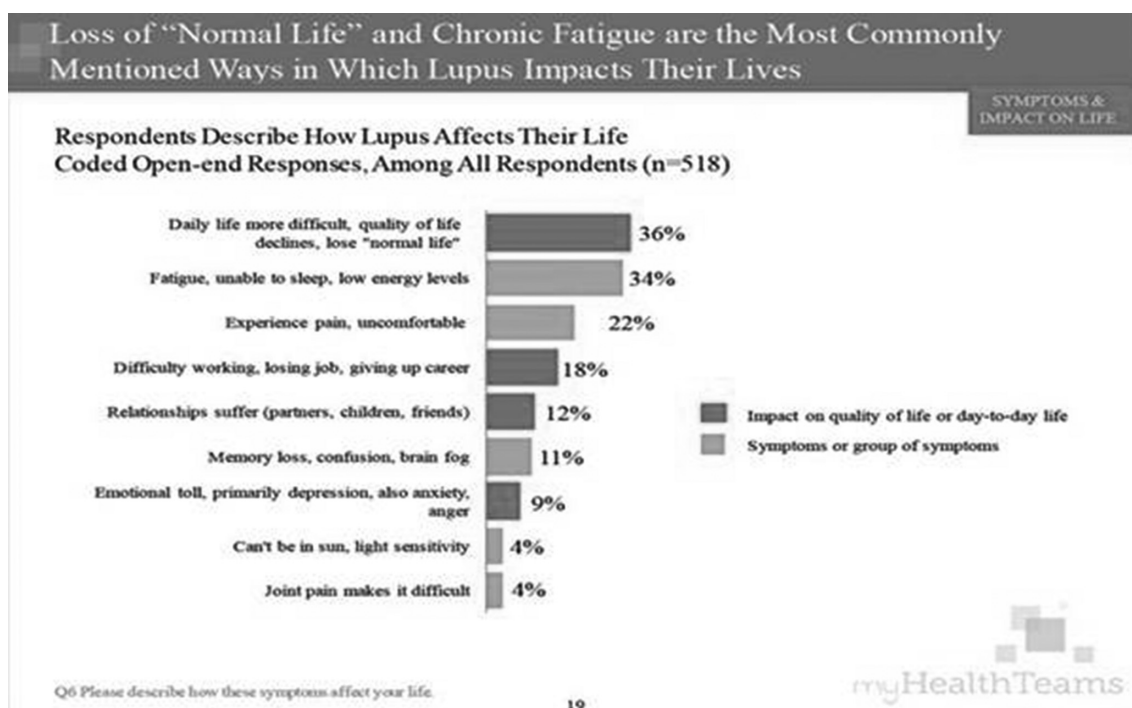
# ASSOCIATION BETWEEN HYPERTENSION AND PROTEINURIA IN SYSTEMIC LUPUS ERYTHEMATOSUS

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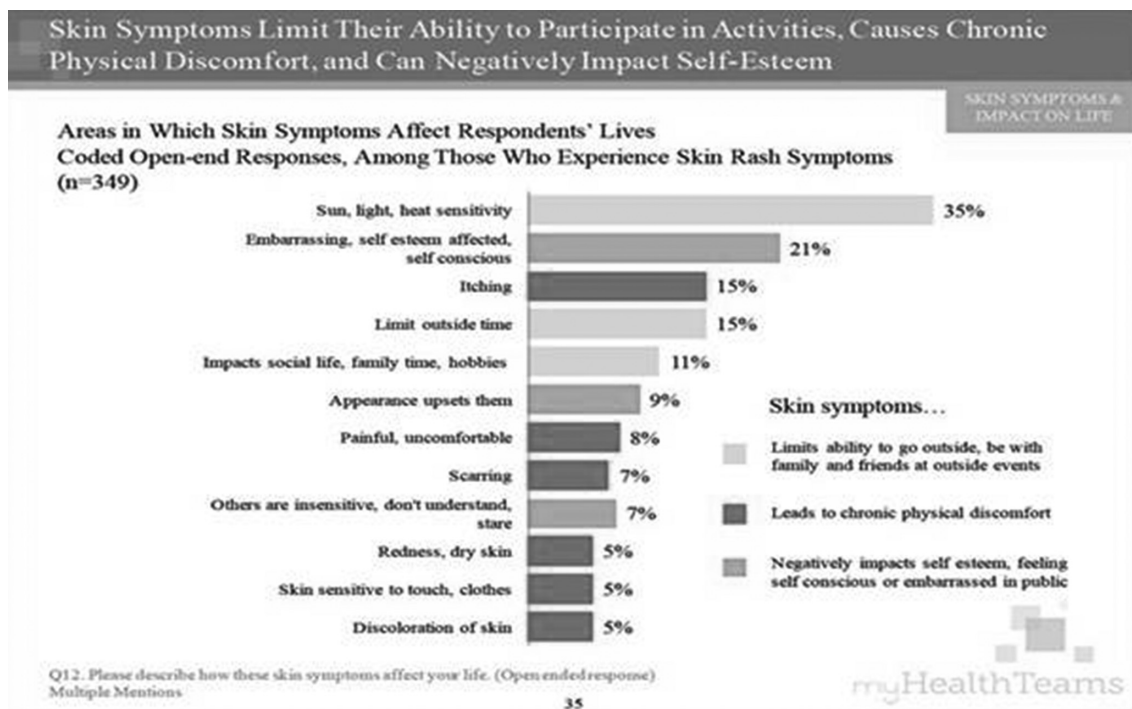
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**Background and aims** Hypertension is one of the most common comorbidities in patients with systemic lupus erythematosus (SLE). We aim to determine the association between hypertension, proteinuria, and elevated serum creatinine level in SLE.

**Methods** This is a cross sectional study of SLE patients who attended Rheumatology Clinic at Hasan Sadikin Hospital Bandung. Patients were diagnosed with SLE according to American College of Rheumatology (ACR) revised criteria 1997 and/or Systemic Lupus International Collaborating Clinics (SLICC) criteria 2012. High blood pressure ( $\geq 140/90$  mmHg), proteinuria, and elevated serum creatinine level



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Abstract 162 Figure 2

( $\geq 1.6$  mg/dL for men,  $\geq 1.4$  mg/dL for women) were identified from medical record. This study used the data in time the patients were diagnosed. The data of SLE patients from 2008 to 2016 were recorded in RSHS Lupus Registry. Chi-square analyses was performed to determine the association between those variables.

**Results** A total of 428 SLE patients had a median age of 35 years (97.9% female), 64 of them (15%) were hypertensive, 176 SLE patients (41.1%) had proteinuria, and 106 SLE patients (24.8%) had elevated serum creatinine level. Forty one SLE patients with hypertension (64.1%) had proteinuria. Hypertension was associated with proteinuria in SLE patients (95% CI, Pearson Chi-Square 18.948, asymptotic significance  $<0.001$ ). Elevated serum creatinine level had no association with hypertension (95% CI, Pearson Chi-Square 0.071, asymptotic significance 0.789) and with proteinuria (95% CI, Pearson Chi-Square 0.603, asymptotic significance 0.438).

**Conclusions** In this study, hypertension is associated with proteinuria. There are no associations between hypertension and proteinuria with elevated serum creatinine level.

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#### SJOGREN'S SYNDROME AND LOCALISED LOCALIZED NODULAR CUTANEOUS AMYLOIDOSIS: NEW INSIGHTS INTO THE LINK BETWEEN THE TWO

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**Background and aims** Sjogren's Syndrome (SS), a known complication of systemic lupus erythematosus, is associated with localised nodular cutaneous amyloidosis, AL type (AL-LNCA).

The reason is unclear, but clues from studies of this rare variant of amyloidosis are emerging.

**Methods** Six patients with AL-LNCA, 4 from Austria and 2 from Canada were identified. Clinical, demographic and histopathological data were recorded and outcome noted over a median period of 72 months (range 40–144).

**Results** Of 3 men and 3 women (median age 57 years; range 36–72) 1 patient had diabetes mellitus and essential hypertension and another scleroderma. The skin lesions were tan plaques or nodules, 1.5–4.0 cm in size, on the legs (5) and arm (1). Microscopically, bulky deposits of AL amyloid in the dermis/subcutis were associated with light perivascular infiltrates of lymphocytes and monoclonal plasma cells (with kappa (3) or lambda (3) light chain restriction). Two patients developed local cutaneous recurrences of their AL-LNCA 4 and 5 years after presentation. None developed systemic amyloidosis.

**Conclusions** The clinical phenotype and course of AL-LNCA in our series, like those in the literature, mirror those of primary cutaneous marginal zone lymphoma, lymphoplasmacytic variant. This is now included among the larger group of extranodal B-cell lymphomas of MALT. Patients with SS are at risk for the development of MALT lymphomas. These, in turn, are known to be associated with localised peritumoral amyloidosis in internal organs. We submit that AL-LNCA in SS is a manifestation of a MALT lymphoma in the skin.

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#### CORRELATION BETWEEN PLASMA LEVELS OF TNF- $\alpha$ AND CAROTID ARTERY INTIMA MEDIA THICKNESS IN SLE

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