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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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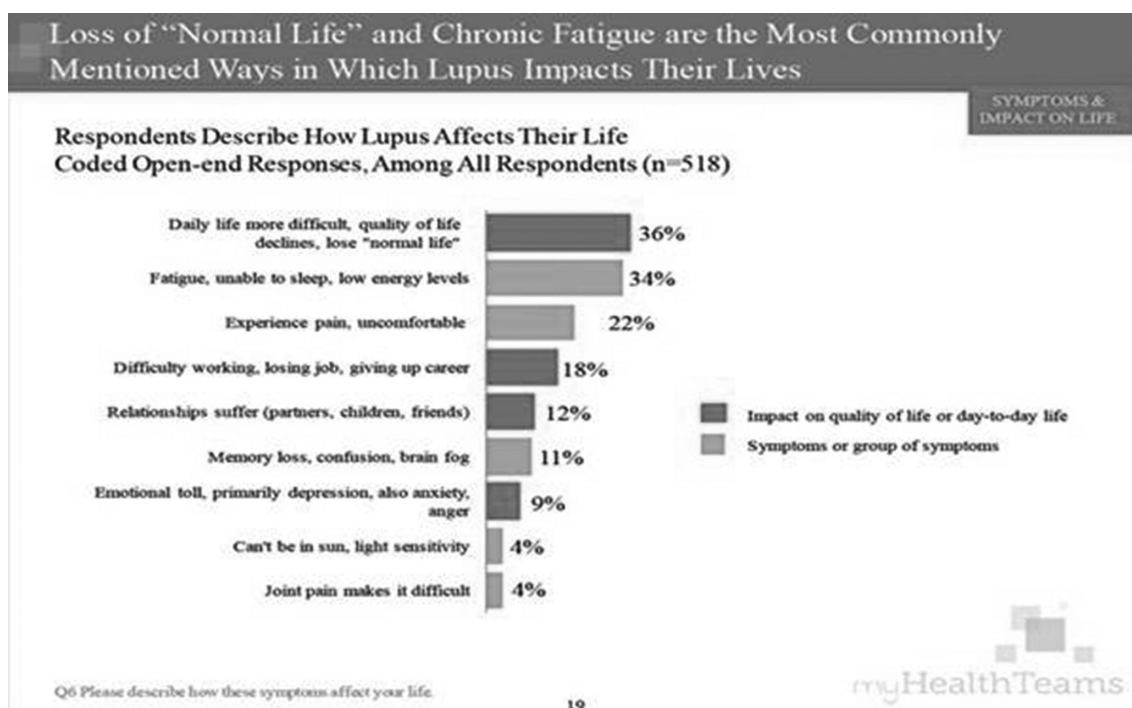
# ASSOCIATION BETWEEN HYPERTENSION AND PROTEINURIA IN SYSTEMIC LUPUS ERYTHEMATOSUS

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**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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