Organ Damage and Its Relationship With Disease Activity in Systemic Lupus Erythematosus: Insights From the Lupus Federated Data Network (LupusNet)

Manuel F Ugarte-Gil,* Rocio V Gamboa-Cardenas, Victor Pimentel-Quiroz, José María Pego-Reigosa, Iñigo Rúa-Figueroa, Marta Domínguez-Álvaro, María Galindo-Izquierdo, Raúl Menor Almagro, Jaime Calvo Alén, Antonio Fernández-Nebro, Julia Martínez-Barrio, Rangi Kandane-Rathnayake, Eric Morand, Worawit Louthrenoo, Alberta Hoi, Mandana Nikpour, Sandra Navarra, Chak Sing Lau, Laniyati Hamijoyo, Yeong-Jian Jan Wu, Yasuhiro Katsumata, Mercedes García, Guillermo J Pons-Estel, Eduardo Kerzberg, Micaela A Cosatti, Odirlei Andre Monticielo, Iris Guerra Herrera, Gerardo Quintana-Lopez, Hilda Fragoso-Loyo, Armando Calvo, Vicente Juárez, Carolina Bobadilla Mendez, Sarah Gasman, Catherine Yount, Anna Sheahan, Joerg Ermann, Stephen Fortin, Michel van Speybroeck, Reyhan Sonmez, Federico Zazzetti

*Presenting author.

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Key Takeaways

- **Over 3 years of follow-up, organ damage accrued across all disease activity categories, including among patients whose maximum SLEDAI-2K score remained in the mild range**
- **Organ damage accrued in patients with no previously reported damage across all disease activity categories**
- **These findings reinforce the importance of longitudinal monitoring and damage-prevention strategies in SLE**
- **The geographic breadth and harmonized structure of LupusNet provide an important platform for characterizing long-term SLE outcomes across diverse populations and generating evidence to inform future research on organ damage prevention**

Background

- Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that is characterized by a heterogeneous clinical presentation and recurring patterns of relapse and remission[1,2]
- Disease activity and irreversible organ damage are key determinants of prognosis in SLE[3,4]
- Organ damage is conventionally defined as persistent change present for ≥6 months[3,4]
  - This is clinically distinct from active inflammation[2,3]
- Organ damage can accrue throughout the course of SLE and contributes substantially to long-term morbidity, which makes the prevention of irreversible damage an important objective alongside control of disease activity[4]
- The Lupus Federated Data Network (LupusNet) harmonizes data from existing longitudinal SLE registries across multiple geographic regions, which enables consistent analyses of clinical characteristics and outcomes while data remain within the participating networks[5]
  - LupusNet currently aggregates data from 5 major, longitudinal, observational registries of patients with SLE that are located in the Asia-Pacific region, North America, Europe, and Latin America
  - The registries include the Asia Pacific Lupus Collaboration (APLC), The National Databank for Rheumatic Diseases (FORWARD), the Lupus Register of the Spanish Society of Rheumatology (RELESSER), the Grupo Latino Americano De Estudio de Lupus (GLADEL 2.0), and the Almenara Lupus Cohort (Almenara)

Objective

The present study used data from LupusNet to evaluate the prevalence of organ damage at registration (registry enrollment) and the accrual of new damage during a 3-year observation period by SLE disease activity status

Methods

- Data were analyzed from 4 SLE registries mapped within LupusNet: APLC (Asia Pacific), RELESSER (Europe), and Almenara and GLADEL 2.0 (Central and South America)
- Disease activity was assessed at registration and follow-up visits using the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K)
  - Patients with ≥3 years of follow-up were categorized according to the maximum SLEDAI-2K score recorded from registration through Year 3: mild (≤4), moderate (>4 to <10), or high (≥10)[5]
- Damage accrual was assessed using the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI) scores during a 30-day window before and after registration and at Year 3
- Analyses examined baseline damage prevalence, new damage accrual, and distribution of damage types across disease activity groups

Results

Study Population

- A total of 3734 patients were included (**Table 1**)
  - Compared with patients with a maximum of mild or moderate disease activity over the 3-year follow-up, those with high disease activity, on average, were younger and had a shorter time from SLE diagnosis to registration

TABLE 1: Baseline characteristics by the maximum SLEDAI-2K score over follow-up

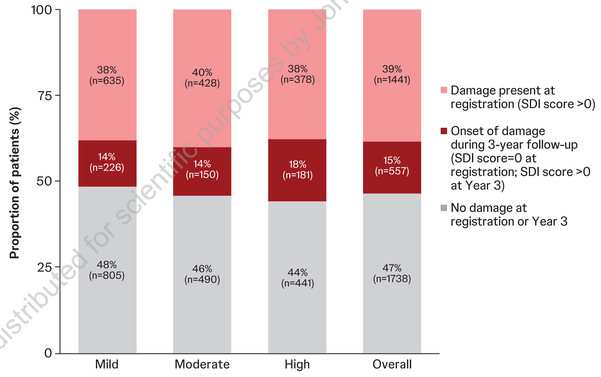
Characteristic	Mild	Moderate	High	Overall
n at registration (% of overall)	1666 (44.6)	1068 (28.6)	1000 (26.8)	3734 (100)
Female, n (%)	1532 (92)	977 (91)	921 (92)	3430 (92)
Mean (SD) age at registration, y	45.8 (13.1)	42.2 (12.5)	37.0 (11.8)	42.4 (12.9)
Mean (SD) duration from SLE diagnosis to registration, y	12.0 (8.4)	10.6 (8.0)	8.8 (7.5)	10.7 (8.1)

Mild: SLEDAI-2K score ≤4; moderate: SLEDAI-2K score >4 to <10; high: SLEDAI-2K score ≥10.
SD=standard deviation, **SLE**=systemic lupus erythematosus, **SLEDAI-2K**=Systemic Lupus Erythematosus Disease Activity Index 2000.

SDI Damage Accrual Through 3 Years of Follow-Up

- In the overall cohort, the proportion of patients with any recorded organ damage (SDI score >0) increased by 15 percentage points from 1441 of 3734 (39%) patients at registration to 1998 of 3734 (54%) patients at Year 3 (**Figure 1**)
- Damage accrual was observed across all disease activity categories
  - Among patients with no damage at registration, new damage developed in 226 of 1666 (14%) patients with mild disease activity, in 150 of 1068 (14%) patients with moderate disease activity, and in 181 of 1000 (18%) patients with high disease activity by Year 3
  - At Year 3, 1738 of 3734 (47%) patients in the overall cohort had no recorded damage; this corresponded with 805 of 1666 (48%) patients with mild, 490 of 1068 (46%) patients with moderate, and 441 of 1000 (44%) patients with high disease activity

FIGURE 1: Damage accrual during 3-year observation in patients with SLE in LupusNet by disease activity categories

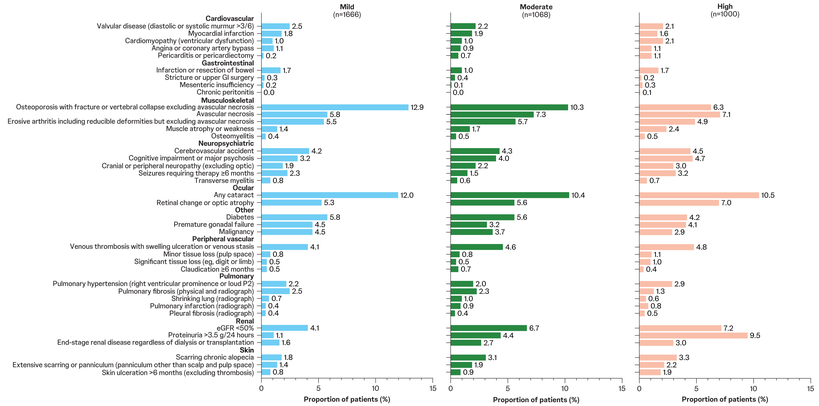


Mild: SLEDAI-2K score ≤4; moderate: SLEDAI-2K score >4 to <10; high: SLEDAI-2K score ≥10.
SDI=Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index, **SLE**=systemic lupus erythematosus, **SLEDAI-2K**=Systemic Lupus Erythematosus Disease Activity Index 2000.

SDI Damage Types at Year 3

- Overall, the most common damage manifestations present at Year 3 were osteoporosis with fracture and cataracts (**Figure 2**)
  - At Year 3, renal damage was more prevalent in patients with high disease activity
  - At Year 3, osteoporosis-related damage and cataracts were more prevalent among those with mild disease activity, which may reflect the older age and longer disease duration in this group

FIGURE 2: Distribution of SDI damage types present at Year 3 by disease activity category



eGFR=estimated glomerular filtration rate, **GI**=gastrointestinal, **P2**=pulmonic valve closure sound, **SDI**=Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index.

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