

LIVING WITH SYSTEMIC LUPUS ERYTHEMATOSUS IN 2024: LATIN AMERICAN EXPERIENCE BASED ON A PATIENT SURVEY

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BACKGROUND

Systemic lupus erythematosus (SLE) is a systemic autoimmune disease that significantly impacts patients' quality of life. In 2020, a survey was conducted by Lupus Europe to assess the burden of SLE among European patients¹. The reality of Latin America (LA) is highly diverse in terms of healthcare access and treatment availability, making it essential to describe these experiences from the patients' perspective. This study aimed to evaluate the burden of SLE from the perspective of LA patients in 2024.

RESULTS

Data from 2,139 SLE respondents (95.9% female, median age: 38.0 years [IQR: 31.0–46.0], 25.5% Caucasian, 34.7% Mestizo, 20% Afrolatinoamerican, 10% indigenous and 6.8% other) from 15 LA countries were analyzed. The most commonly affected organs were the joints (68.1%), the skin (47.3%), and the kidney (35.6%). In 52.5% of the cases, a previous diagnosis other than SLE was reported. Regarding educational level, 40% had completed high school. At the time of the survey, 40% were employed, while 20% had stopped working due to lupus. Daily life activities were negatively impacted by lupus for 40% of respondents, with joint pain (17.5%) and fatigue (35%) being the most disruptive symptoms. Additionally, 35.6% of patients used antimalarials, 25% were on steroids (mean dose: 5 mg/day), 27.8% used immunosuppressants, and 5.4% were receiving biologic drugs. Notably, 35% of respondents agreed that they had access to specialized care and treatments appropriate for their condition.

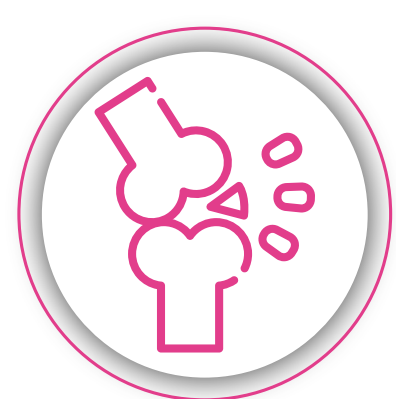
CONCLUSION

Understanding patient perspectives is crucial for evaluating the impact of SLE and addressing challenges related to healthcare access and treatment. Incorporating patient feedback into regional healthcare policies should be prioritized.

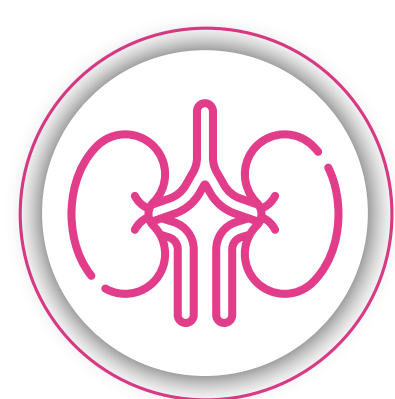
MOST AFFECTED ORGANS



skin

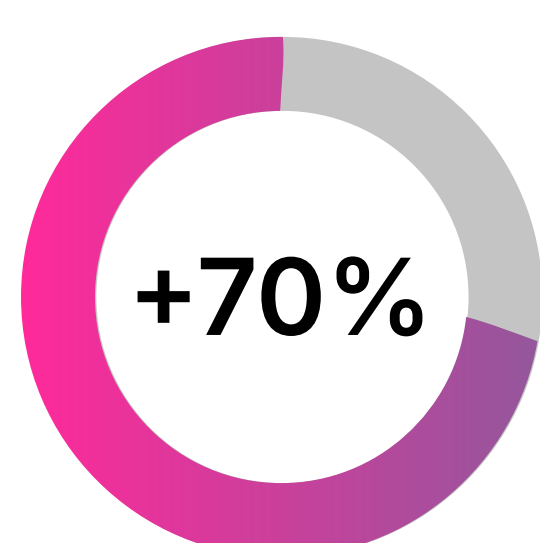


joints

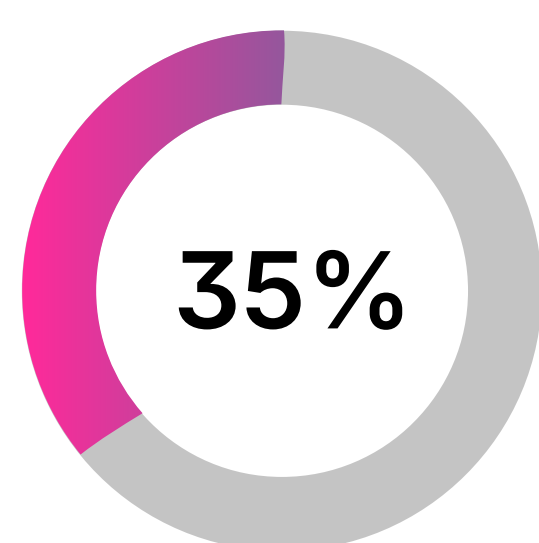


kidneys

QUALITY OF LIFE



feel less active



report negative impact on their emotional, social and family life.

METHODS

In May 2024, as part of the international SLE awareness day, the Grupo Latinoamericano de Estudio del Lupus (GLADEL) disseminated an anonymous, bilingual online survey (in Spanish and Portuguese) to patients diagnosed with SLE through their physicians and various patient associations across LA countries.

PARTICIPATED

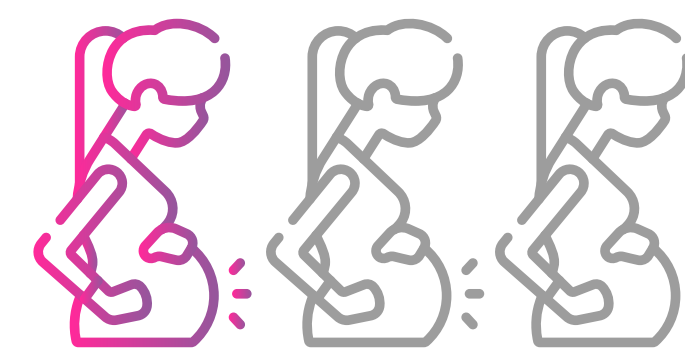
2139
PATIENTS

13
countries in Latin America

PATIENT PROFILE

96% women

50% work actively

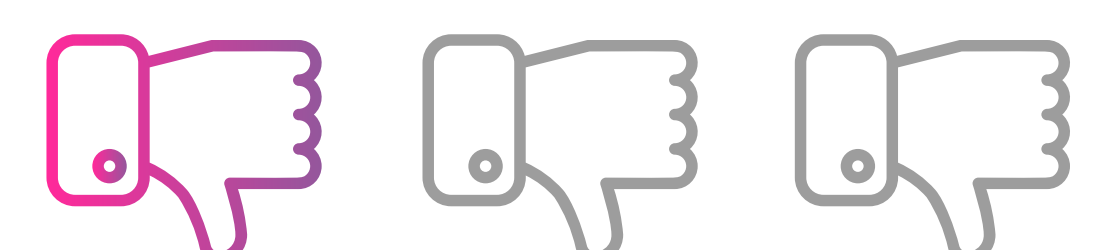


1/3 were mothers

EDUCATION

50% studied a profession

1/3 had difficulty completing their studies



MAIN SYMPTOMS



pain in joints and muscles



hair loss



fatigue

HEALTH CARE

50% feel support from specialists

ACCESS

30% have problems accessing consultation and treatment

REFERENCES

1-Cornet A, Andersen J, Myllys K, et al. Living with systemic lupus erythematosus in 2020: a European patient survey. *Lupus Science & Medicine* 2021;8:e000469. doi:10.1136/lupus-2020-000469

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