

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

Diana Fernandez; Veronica Bellomio; Manuel Ugarte-Gil; Rosana Quintana; Romina Nieto*; Marina Scolnik; Carmen Funes Soaje; Paula Alba; Verónica Saurit; Mercedes Garcia; Guillermo Berbotto; Eduardo Kerzberg; Graciela Gómez; Cecilia Pisoni; Nilzio Antonio da Silva; Luciana Parente; Odirlei Andre Monticielo; Henrique Ataide Mariz; Francinne Machado Ribeiro; Eduardo F Borba; Edgard Torres dos Reis Neto; Iris Guerra Herrera; Loreto Massardo; Gustavo Aroca Martinez; Carlos Alberto Cañas Dávila; Gerardo Quintana López; Mario Moreno; Miguel Ángel Saavedra Salinas; Margarita Portela Hernández; Hilda Fragoso Loyo; Luis H. Silveira; Ignacio García de la Torre; Carlos Abud Mendoza; Jorge A. Esquivel Valerio; María Isabel Acosta; Claudia Selene Mora Trujillo; Katiuzka Zuñiga Corrales; Roberto Muñoz Louis36; Martin Rebella; Vicente Juarez; Carlos Toro; Ana Malvar; Yurilis Fuentes; Alain Cornet; Laurent Arnaud; Bernardo Pons-Estel and Guillermo Pons-Estel.

ID 447
*Presenting Author

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 patients(1). 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.

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.

RESULTS

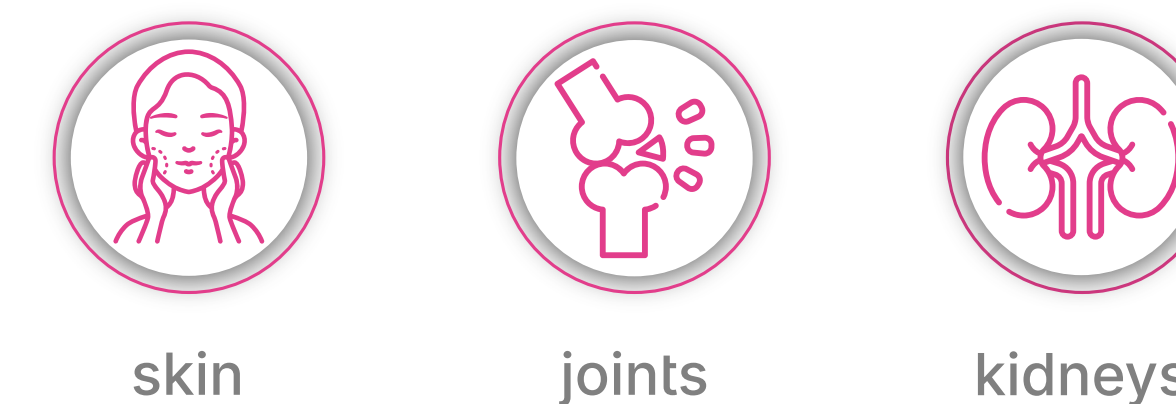
Data from 2139 SLE respondents (95.9% female, median age: 38.0 years [IQR: 31.0–46.0], 25.5% Caucasian, 34.7% Mestizo, 20% Afrolatinoamerican, 10% indigenous and 6.8% other) from 15 LA countries were analyzed. The most commonly affected organs were the joints (68.1%), the skin (47.3%), and the kidney (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.

PARTICIPATED

2139
PATIENTS

13
countries in
Latin America

MOST AFFECTED ORGANS

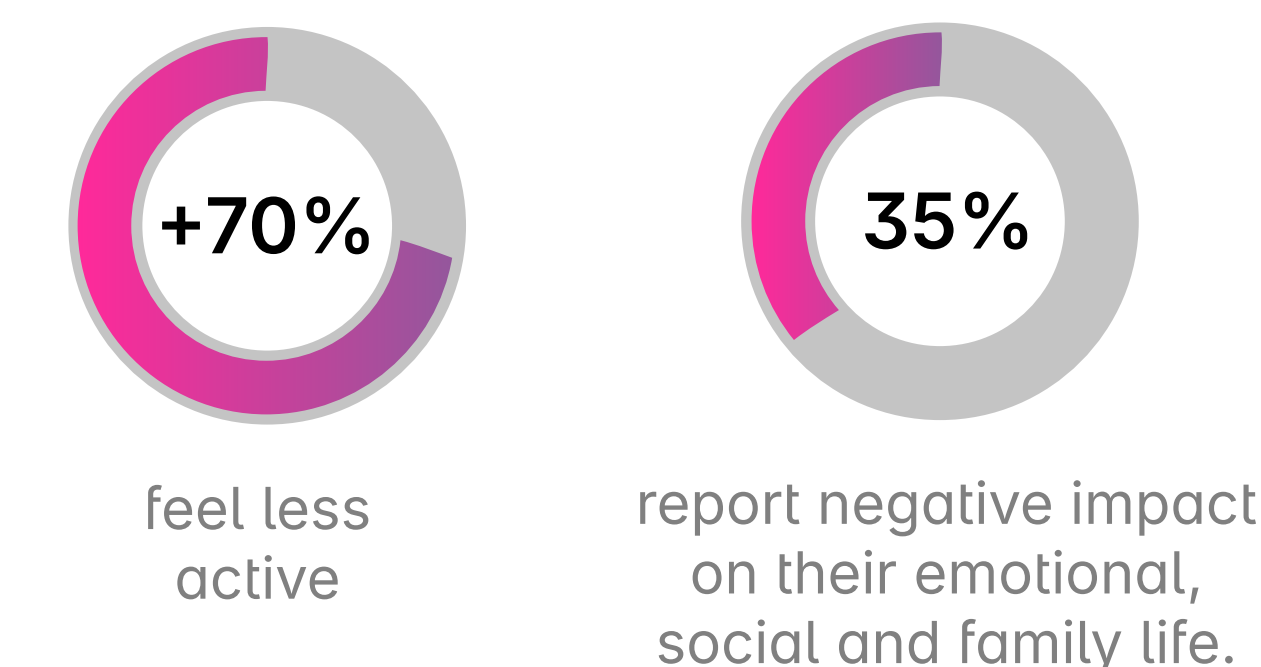


PATIENT PROFILE

96% women
50% work actively

1/3 were mothers

QUALITY OF LIFE



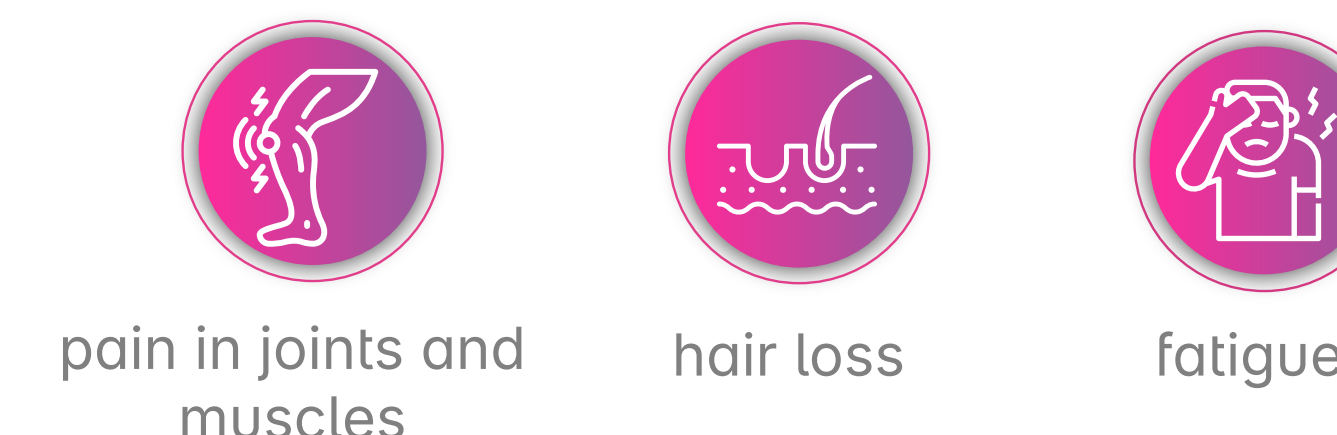
CONCLUSION

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.

EDUCATION

50% studied a profession
1/3 had difficulty completing their studies

MAIN SYMPTOMS



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

ACKNOWLEDGMENTS

LUPUS EUROPE for the support in adapting the survey to LA, to the GLADEL researchers and all patients who voluntarily participated in this survey and to the patient associations that made the survey available to patients.

