



DELAY IN DIAGNOSIS AND TREATMENT OF PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS IN LATIN AMERICA. A MIXED METHODS STUDY.

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BACKGROUND

Systemic lupus erythematosus (SLE) is a complex disease associated with significant early morbidity and mortality. Approximately 30% of patients with SLE experience diagnostic delays, with means ranging from 3 to 5 years. In Latin America (LA), the disparities in healthcare access and availability of specialized consultations across countries underscores the need to establish timelines and evaluate factors impacting key stages in the patients’ healthcare journey. This study aims to describe the process of seeking care, as well as delays in diagnosis and treatment, and to identify associated factors—barriers, facilitators, and patient needs—among SLE patients receiving care at various rheumatology centers in LA.

METHODS

This is a mixed methods (qualitative and quantitative) study in four phases with a sequential design, in which research outputs from each phase will serve as the foundation for subsequent phases. Phase 1: Evidence Generation - Identify the process of seeking care and define the concept of diagnostic delay through a systematic literature review and development of an interview guide for patients and rheumatologists. Phase 2: Qualitative Analysis - Describe and analyze the patient journey in SLE from the perspectives of both patients and rheumatologists. Phase 3: Questionnaire Development and Validation - Develop and validate a questionnaire to measure care delays and associated factors. Phase 4: Quantitative Analysis - Use the validated questionnaire to assess diagnostic and treatment delays in SLE patients across LA with a representative patient sample. The project is scheduled for the 2023-2027 period and is funded by a grant from PANLAR and the Latin American Lupus Study Group (GLADEL).

CONCLUSION

SLE is a heterogeneous disease that is challenging to diagnose and requires early treatment initiation. Patients and rheumatologists agree that delays in SLE diagnosis have specific characteristics, including disease variability, diversity of healthcare systems, educational factors among health professionals and the general population, and sociocultural and economic conditions. Measuring these delays is essential to provide evidence for informed decision-making in health policies at both national and regional levels.

RESULTS

Seventeen countries in Latin America are currently participating:

Argentina	Honduras
Bolivia	Mexico
Chile	Nicaragua
Colombia	Panama
Cuba	Paraguay
Dominican Republic	Perú
Ecuador	Uruguay
El Salvador	Venezuela
Guatemala	

PHASES



Quantitative and qualitative systematic reviews been completed, and interview guides for rheumatologists and patients have been developed (Phase 1).



Focus groups and in-depth patient interviews are currently underway, simultaneous with qualitative data analysis (Phase 2). Based on a sample design aligned with the epidemiological data of each country, the following activities will be conducted: Phase 2 - 23 focus groups with rheumatologists (an average of 8 participants per country), and 153 individual in-depth patient interviews.



Phases 3 and 4 - 150 patients for the pilot test, 450 patients for questionnaire validation, and 13,369 patients for the measurement of diagnostic delays.

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