PANLAR 2025
27 CONGRESO PANAMERICANO DE REUMATOLOGÍA
PAN-AMERICAN CONGRESS OF RHEUMATOLOGY
CONGRESSO PANAMERICANO DE REUMATOLOGIA

April 23-26, 2025
Expo Santa Fe
Ciudad de México

PANLAR
PAN AMERICAN LEAGUE OF ASSOCIATIONS FOR RHEUMATOLOGY

Submission N°: PANLAR2025-1267

Representations of Masculinity, Narratives of Resilience, and Their Influence on the Understanding and Treatment Adherence of Lupus in Young and Adult Men

Dra. Laura I. Athié Juárez *
laathie@gmail.com

Introduction

In men, approximately 15-20% of systemic lupus erythematosus (SLE) cases are diagnosed before the age of 18. The main challenges in treatment adherence for adolescents and men with lupus involve social, psychological, and medical factors. For adolescents, the typical sense of invulnerability during this stage often leads them to underestimate the importance of treatment. Social pressure and the need to conform to socially designated male roles also impact how symptoms are explained and the consistency with socially visible treatments, such as taking medication or avoiding sun exposure. As men grow older, they face challenges related to gender norms, where admitting to a chronic illness or adhering to long-term treatment is often perceived as a sign of weakness. This perception influences their understanding of the importance of sustained medical care. Additionally, the possibility of a lupus diagnosis is hindered by the misconception that lupus is a "women's disease." Consequently, unlike women, adolescents and men with lupus often have limited access to emotional support networks. For men, this, combined with inadequate education about lupus, further complicates treatment adherence.

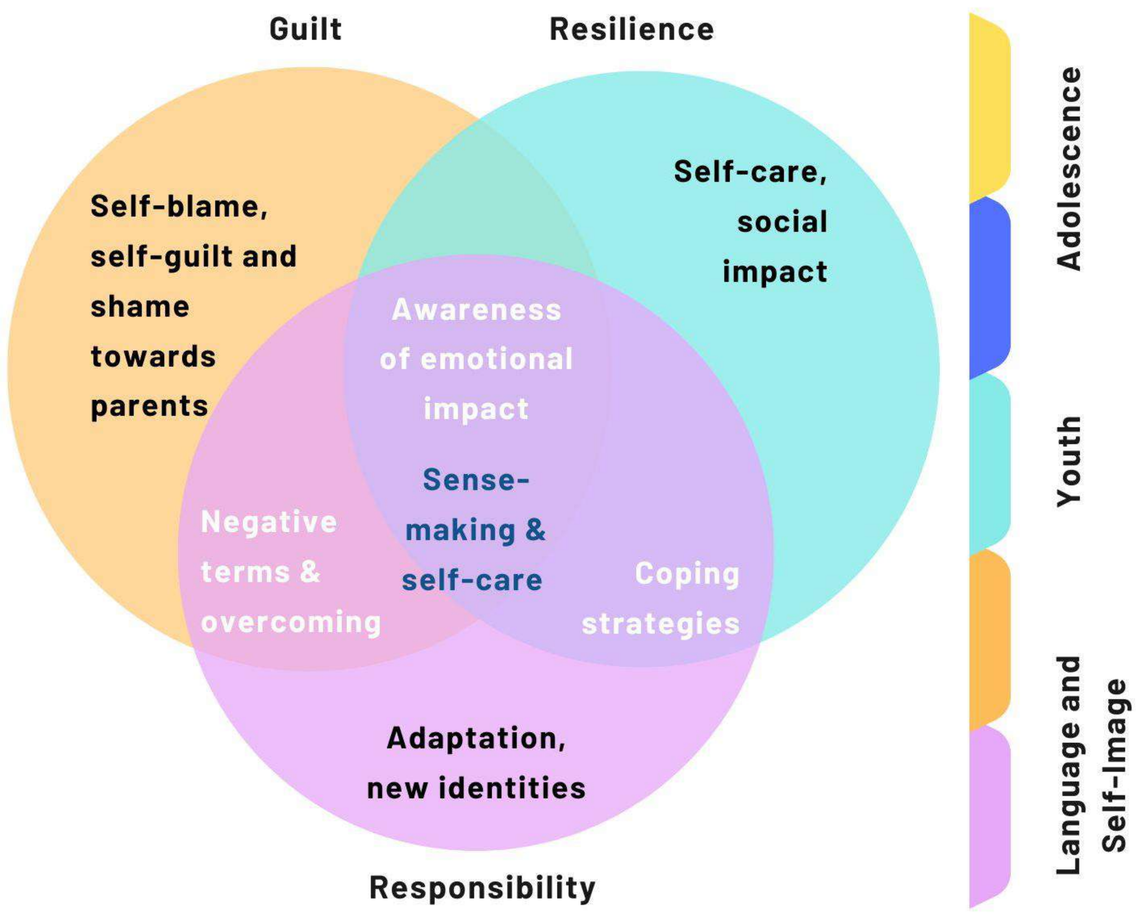
Objectives

Analyze the **identity reconfiguration of adolescent and adult men with lupus** through discursive language patterns and conceptualizations of masculinities surrounding the disease, the perceptions of SLE, and the barriers to adapting to and understanding the illness, using a language-based approach grounded in autobiographical narratives.

Results

Based on a corpus of **352 testimonies from Mexico and other countries**, collected from individuals between 11 and 65 years of age, the sample was observed over a continuous 8-year period. For long-term interviews, 22 were conducted, from which analyses of interviews with adolescents, young adults, and adults with SLE were derived. In 2024, two additional interviews were conducted with young Mexicans with lupus. The analysis also includes a digital survey completed by 330 participants.

The analysis allowed us to define the main representations of masculinity that influence the lupus-related imaginaries of young people as they transition to adulthood, the verbal and mnemonic forms of resilience that shape their attitude toward the disease, and the attitudinal barriers that hinder treatment adherence. A discursive corpus was compiled, enabling the identification of the guilt that young people and adults carry as a result of the disease (See Table 1), using the methodology of Grounded Theory.



* Source: (Athié, 2024) Own elaboration

Methods

Mixed (quantitative-qualitative) longitudinal study. From 2015 to 2023, people with SLE from Mexico, Latin America, the United States, and Europe were invited to participate. Autoethnographic techniques and in-depth interviews were used for the qualitative part, autobiographical letters and hand-drawn illustrations by adolescents and young people were analyzed, while a digital survey was employed for the quantitative part. A critical-linguistic and performative analysis of discourse was conducted. Through Grounded Theory, categories related to the lives of men with lupus were derived, allowing for an understanding of how men experience SLE and the biographical forms in which they express pain. Among the variables considered were: ***a)*** conceptions of male identity before and after diagnosis in adolescents, and ***b)*** self-designations in language following diagnosis up to maturity, across the stages of the illness.

Table 1. Main Discursive Forms of Self-Blame, Resilience and Masculinities in Young Individuals with Lupus*.

Category	Description	Discursive Fragments
Main Discursive Forms of the Self	Ways in which **young men** perceive and express their identity in the face of the disease.	- "I became more mentally active (...) to avoid being somewhat restless." - "This character helps you either move forward or fall behind." - "Lupus does change your life, but it also builds character."
Forms Guilt	Expressions of **self-blame** for the burden placed on their family or for previous behaviors.	- "Those resources my family needs are dedicated to me and not to my siblings." - "I regret being so restless before the diagnosis."
Ways of Resilience	Strategies to **adapt and cope with the disease**, linked to discourses about responsibility.	- "If you know how to have good control over your thoughts and emotions, we can handle it." - "I have managed to move forward (...) if we keep it under control, we can move forward."
Discursive Forms Representing Masculinities	Discourses linked to **traditional gender roles** and cultural expectations about men.	- "Character helps you move forward." - "I want to help my parents and have a house." - "Lupus sets very difficult challenges in life, but with responsibility, we can handle it."

* Source: (Athié, 2024) Own elaboration

Conclusions

From the findings of this research, several representations of masculinity emerge that are assumed after receiving a lupus diagnosis. Additionally, forms of **self-blame** arise during adolescence and youth, directed both at oneself and at parents for having the disease. In adulthood, self-blame shifts towards the damage and changes the disease causes to the body, as well as its impact on social, professional, and family life. Similarly, **discursive forms of resilience** are identified, alongside **violent self-denominations** that disable men from a self-conception shaped by lupus. These conceptions are constructed throughout the individual's life history, with visible markers in their narratives and a particular vocabulary tied to the disease.

Responsibility and resilience stand out as central themes in the masculine discourses, where young men perceive themselves as the primary individuals responsible for their care. **Guilt emerges as a constant,** directed both toward themselves and their families, primarily due to the economic and emotional impact of the disease. Traditional masculinities, such as strength and the ability to overcome obstacles, influence the way young men interpret and manage their condition.

The narratives analyzed from young people and men with lupus reveal findings that pinpoint the moments when language defines how the individual's sense of self changes, when and under what circumstances they adhere to or deviate from treatment, when **they blame the disease** for what happens to them, the stages in which they choose to persevere, and the discourses of resilience that could provide valuable insights for medical treatments and care strategies.

* Doctor and Master in Language Sciences (ICSyH BUAP), president of the Athié-Calleja Center for Transdisciplinary Studies for the rights of people with lupus A.C. Co-director of LEM: Center for the Production of Readings, Writings and Memories. Master in Educational Policy (IIEP UNESCO Paris), Specialist in Education (IIEP Buenos Aires and FLACSO México). Communicator (UABC). Diploma in Narrative Therapy (ILEF). Since 2006, she has been investigating testimonies of people with lupus.

**This paper derives from the research "Counternarratives to discursive violence: The case of people with lupus" (Institute of Social Sciences and Humanities, Benemérita Universidad Autónoma de Puebla, Athié, 2023), which was awarded Cum Laude and which analyzes the identity reconfiguration of those who suffer from SLE based on the impact of symbolic (Bourdieu, 1989), daily (Scheper-Hughes and Bourgois, 2004), structural (Farmer, 1999, 2004) and discursive violence (Athié, 2021). https://hdl.handle.net/20.500.12371/19986