



XL COMU Awards 2021 – Clinical

Social impact of disease parameters and damage accrual in patients with juvenile-onset systemic Lupus Erythematosus: a multicenter cross-sectional study

**Nicolas Yamada Tanigava, Ana Paula Sakamoto, André Silva Franco,
Lucas Peixoto Sales, Nadia Emi Aikawa, Maria Teresa Terreri,
Rosa Maria Rodrigues Pereira***

Universidade de São Paulo, Faculdade de Medicina (FMUSP)

*Orientador

ABSTRACT: *Objectives:* To describe the frequency and investigate potential associations of unemployment, need of financial assistance and health-related quality of life in adult patients with Juvenile-onset Systemic Lupus Erythematosus (JSLE). *Methods:* In this multicenter cross-sectional study including JSLE adult patients, questionnaires were applied evaluating demographic characteristics, medical history, treatment, government financial assistance and work status, quality of life, economic classification, disease activity and damage accrual. *Results:* Sixty-nine JSLE patients from two Brazilian tertiary centers were included in this study. Twenty-eight (40.6%) patients were unemployed and 16 (23.2%) were receiving financial assistance or retirement. Work unemployment was associated only with higher damage scores (OR 1.95, 95% CI 1.14 to 3.35, $p = 0.015$), while the need of financial assistance was associated with higher damage scores (OR 1.83, 95% CI 1.02 to 3.27, $p = 0.042$), longer disease duration (OR 1.15, 95% CI 1.01 to 1.32, $p = 0.043$) and worse economic score (OR 0.87, 95% CI 0.76 to 0.99, $p = 0.036$). Emotional health, body image perception and pain were the most compromised domains of quality of life but showed no correlation with disease parameters. Disease activity, on the other hand, was inversely associated with symptoms scores ($\rho = -0.34$, $p = 0.004$) and scores of adverse effects of medications ($\rho = -0.27$, $p = 0.024$). *Conclusion:* JSLE is a disease with severe outcomes and high social burden that profoundly impact patients during adulthood. Damage accrual is the main risk factor for both unemployment and need of financial assistance and its prevention must be central in the management of JSLE patients.

Keywords: Systemic lupus erythematosus; Cost of illness; Unemployment; Quality of life.