

CIORA-Funded Study Shines: Podium Presentation and Quality Care Initiatives in Rheumatology Award Winner SLE: A National Mixed-Methods Sequential Explanatory Study

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Work is central to people's lives, as it positively impacts individuals' physical, mental, financial, and social health and well-being. Multidisciplinary collaborative practice offers a practical solution that permits the delivery of complex care that can also be patient-centered. Patient- and clinician-reported functional outcomes measure various domains of work disability and function. Patients with systemic lupus erythematosus (SLE) experience physical and mental challenges that hinder their ability to work. The unpredictable disease course of SLE with its remitting and relapsing phases results in changing levels of work disability and functioning in a patient's life, making it difficult to deliver patient-centered care. Work disability and function have a complicated starting point that includes the study of issues under the patients' control and those in their environment. The link between work and lupus is an important individual concern because of the significant influence of work on different aspects of a patient's health, including engaging in meaningful activities. **Our study proposes a novel evidence-based intervention to mitigate work disability.**

CIORA-CRA funding has been instrumental in allowing us to meet the study objectives. Specifically, in this national Canadian study, we developed a functional profile that will provide an initial understanding of the effect of the disease on a patient's daily functioning. A primary concern in functional assessment is the evaluation of a patient's ability to engage in work. A functional profile is defined as activities of daily living and those related to work functioning (e.g., instrumental activities of daily living, such as managing finances and transportation).¹ We collected data from 404 participants from seven centres across Canada, with a mean age of 47.0 ± 13.7 years. Regarding functioning, the total and subscale scores were comparable to a cancer diagnosis population or a common mental disorder population. Second, the study has identified factors associated with work disability and generated thoughts on improving patient care and work participation. Finally, to explore the li-



ved experiences (a patient's lived situations and perspectives) of SLE patients during their return to work journey, most participants experienced some form of work disability across their employment history related to their clinical manifestations of SLE, including hospitalizations, physi-

cal limitations in engaging in activities of daily living, fatigue, and neurocognitive symptoms (e.g., brain fog). Thematic analysis revealed three key themes: a) the influence of illness experience on work, b) stigmatization of illness disclosure, and c) availability of workplace resources/accommodations.² Participants emphasized the importance of employment characterized by reduced physical and mental demands, enhanced personal autonomy, and increased workplace flexibility as measures to prevent work-related disabilities.

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References

- Nowrouzi-Kia B, Avina-Zubieta J, Fox M, et al. Work Disability and Function in Systematic Lupus Erythematosus (SLE): Results from a Mixed-Methods Exploratory Canadian Study [abstract]. AR, 2022 Nov 13 [cited 2025 Apr 23]; 74 (suppl 9).
- Nowrouzi-Kia B, Howe A, Li A, et al. Work disability in patients with systemic lupus erythematosus: a Pan-Canadian qualitative study [poster presentation]. J Rheumatol. 2024 Jul;51(Suppl 1):43-98. doi:10.3899/jrheum.2024-0330_poster_presentations.