

Canadian workplace experiences of systemic lupus erythematosus (SLE)

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To cite: Cardwell FS, Dixon J, Clarke AE, *et al.* Canadian workplace experiences of systemic lupus erythematosus (SLE). *Lupus Science & Medicine* 2021;**8**:e000536. doi:10.1136/lupus-2021-000536

Received 13 July 2021

Accepted 8 September 2021



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SLE impacts the individual's ability to engage in meaningful employment. Disease-related un(der)employment has substantial direct and indirect costs,¹ as well as psychosocial and relationship impacts.² These costs disproportionately affect already disadvantaged populations. With the demonstrated adverse economic and psychosocial impacts related to ceasing work prematurely, maintaining employment is recognised as both a positive health intervention and societally beneficial. Workplace policies and labour laws in many jurisdictions, including Canada, mean that individuals with disabilities should be reasonably accommodated to maintain participation in the workforce. Yet the specific challenges of SLE for employment (eg, fatigue, invisibility to others, periodic flares) are not captured by current legislation³ despite one-fifth of those with SLE being unable to work.^{4,5}

The limited research on job accommodations in SLE focuses primarily on rheumatoid and osteoarthritis.⁶ One notable exception is a Canadian cross-sectional study indicating those who maintained employment and those who left equally reported having attempted at least one form of job accommodation (70% and 72%, respectively), but those who remained employed had more opportunities to access a variety of accommodations including altering their own work schedules.⁷ However, the study could not speak to the decision to disclose, experiences of accommodations offered/used, whether they were perceived as beneficial or the contextual factors influencing those who ultimately left the workforce. This is essential information to support meaningful employment for those with SLE.

We investigated the challenges of maintaining employment and the potential for job accommodations to meet these challenges using a qualitative integrated knowledge translation approach.² We sought to understand the context for when SLE diagnoses are disclosed to the employer as the first step towards receiving accommodations, job

accommodations experienced as helpful to maintaining employment and contexts when accommodations did not maintain employment. Whereas quantitative data inform our understanding of certain aspects of SLE research on employment (eg, indirect costs from lost workforce/non-work productivity,¹ proportion of those affected who cannot work,^{4,5} proportion implementing job accommodations⁷), qualitative data provide rich understanding of the personal experiences and decisions of those with SLE. Both types of data are critical to inform policy and practice, and their contributions are complementary (figure 1).

Using maximum variation purposeful sampling, we sought Canadians above 18 years of age who self-reported a physician diagnosis of SLE. Participants (n=29) were recruited through email invitation via patient support organisations, posted invitation through a lupus clinic and snowball sampling through lupus support networks. Recruitment ceased when the research team agreed that thematic saturation had been reached. Participants were predominantly female (n=27) and ranged from mid-20s to late 70s in age (mean=51.14), with most reporting disease onset between 20 and 40 years (mean=32.06). Participants self-reported SLE complications impacting their working life, including although not limited to extreme fatigue (n=22), joint and muscle pain (n=16), and cognitive fog or difficulty concentrating (n=6). At the time of interview, participants were employed full-time (n=12), part-time (n=5), self-employed (n=3; varied hours), unemployed (n=2), retired (n=4) or unemployed but receiving disability insurance payments (n=3). Fourteen participants were open about their SLE with their employer and seven had partially disclosed (eg, to immediate manager but not to the company, disclosed only an unspecified medical issue). Of these 21, 9 reported successfully obtaining job accommodations (in 2 cases, additional accommodations were later denied). Six participants were in positions which already

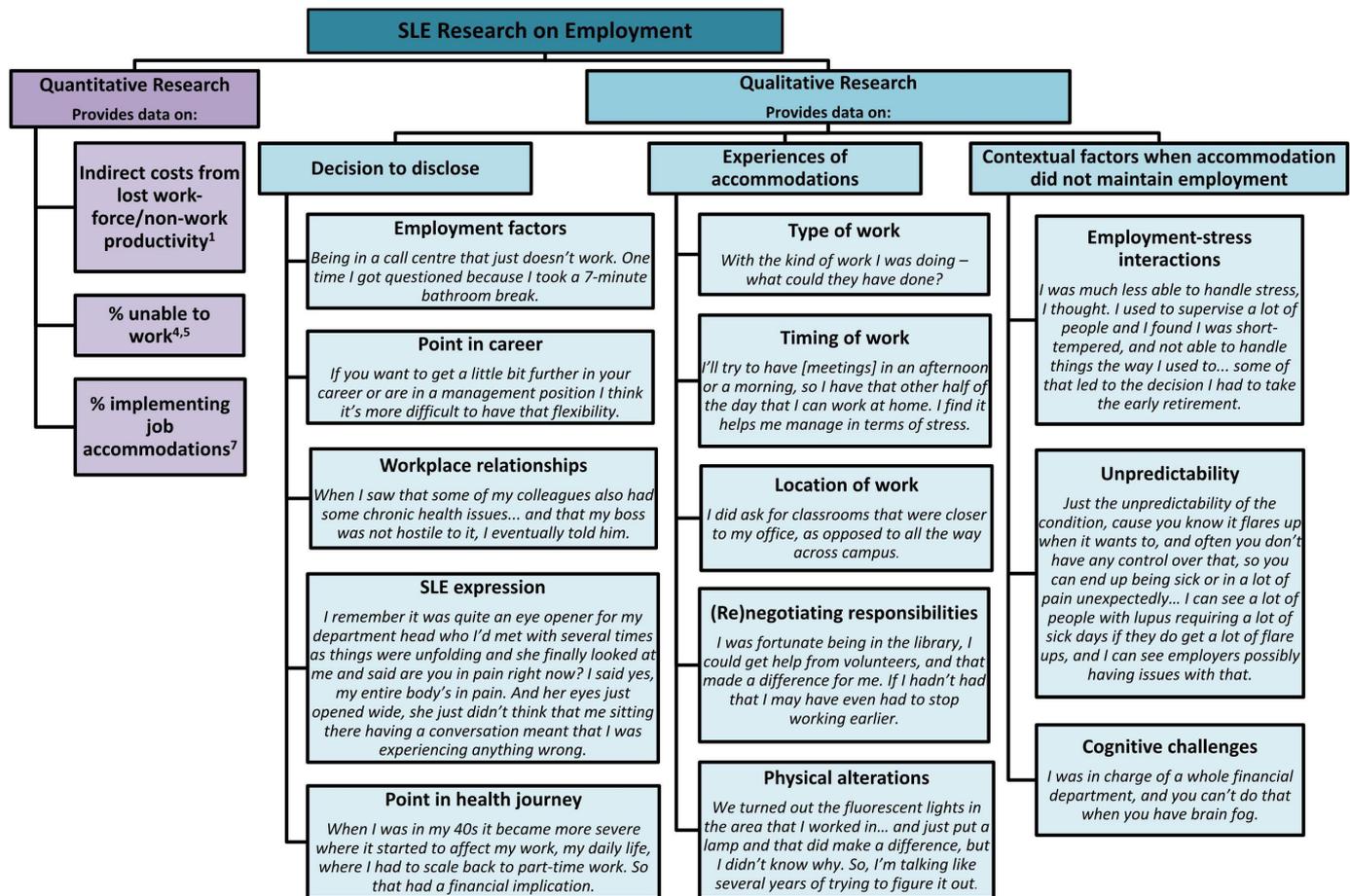


Figure 1 SLE research on employment: quantitative and qualitative contributions to knowledge.

provided desired options (eg, flexible time) and therefore did not require disease disclosure or official accommodation. Additionally, key informants were purposely selected based on their medical or advocacy involvement with SLE in Canada. Five representatives from patient advocacy groups (from four Canadian provinces, one national) and three specialist lupus physicians participated.

Interviews were analysed both inductively (in vivo codes reflecting unanticipated ideas) and deductively (based on research objectives, literature review). **Figure 1** provides a visual representation of the voices of the participants and how they represent the key themes emerging from this work.

While disclosing to the employer is the first step to receiving job accommodations, participants spoke of varied personal calculations regarding the risks and benefits of disclosing. Employment factors (eg, physical demands, flexibility of hours, outdoor time requirements), point in their careers (eg, precarious contract work, seniority with higher employment security, ability to seek early retirement), relationships within the workplace (eg, quality of personal relationships, workplace culture), as well as personal health aspects such as SLE expression (eg, invisible, debilitating, interferes with employment duties) and point in their health journey (eg, sudden onset of symptoms, confirmed diagnosis, disease controlled by medication) were identified as potential factors mediating this decision. Those who chose not

to disclose cited fear of stigmatisation impacting career potential and a lack of possible accommodations.

Many living with SLE experience minimal impact on their lives, and indeed some participants in this study did not require any job accommodations. However, several participants described employers who were willing to work with them to provide accommodations that allowed them to remain in their position or shift to a new position. In these cases, participants described job accommodations as beneficial and necessary for maintaining employment. Five subthemes related to how patients experience job accommodations and what they perceive to be helpful or sought after emerged from the data: type of work (manual labour, desk work), timing of work (moving to flextime, part-time/job sharing, availability of leaves of absence), location of work (working from home), renegotiating responsibilities (moving away from intensive or deadline-dependent) and physical alterations (using air filtration systems, reducing use of fluorescent lights, ergonomic chair/desk, reducing physical labour).

Even with demonstrated benefits, providing access to these job accommodations will not completely solve issues of maintaining employment. Importantly, we identified three situations in which participants perceived themselves as too sick to continue working (even with job accommodations available): employment increased stress levels to such a degree that it further triggered the disease (fear of 'waking

up' the lupus), the unpredictable nature of SLE made it too difficult to commit to regular employment, or SLE-related cognitive challenges were impossible to work around. Our interviews did not uncover any clear answers as to how these situations could be fully accommodated. However, this may provide insight into Al Dhanhani *et al's*⁷ finding that some with SLE will try out accommodations, such as moving to part-time, but eventually give up their work. Without clearly addressing the core problems raised here (stress-induced flares, unpredictability, cognitive difficulties), those accommodations may only be acting as a temporary bandage and not a long-term solution.

In sum, affected individuals identified job accommodations as essential for maintaining employment. However, not all employees are comfortable disclosing and seeking accommodations, and in some circumstances the availability of accommodations is not enough to overcome SLE challenges. As such, successful strategies to maintain employment for those with SLE are highly individualised and more work is needed to support the range of experiences. This has implications for who is more likely to disclose and continue in employment, and the subsequent adverse emotional and physical health impacts for those who do not. Understanding how employers can successfully accommodate individuals with SLE is critical to promote healthy employment and reduce the economic burden associated with this disease.

Acknowledgements The authors thank all the participants who provided their time for this research and would also like to acknowledge the generous funding from the Lupus Society of Alberta and the Canadian Initiative for Outcomes in Rheumatology Care (CIORA).

Contributors FSC and JD conducted the data collection and analysis and wrote the initial manuscript. AEC and SJE devised the project and provided oversight and guidance. All authors contributed to the final version of the manuscript.

Funding This project was supported by the Lupus Society of Alberta and the Canadian Initiative for Outcomes in Rheumatology Care (CIORA).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval This research received approval from the University of Waterloo Office of Research Ethics (ORE #21157).

Provenance and peer review Not commissioned; externally peer reviewed.

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