

“Going Down a Different Path”: A Qualitative Exploration of Costs Incurred by Patients with Systemic Lupus Erythematosus (SLE)



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Introduction

Background

- Previous studies investigating the economic costs of Systemic Lupus Erythematosus (SLE) in Canada have focused only on direct costs using quantitative methods
- SLE primarily impacts patients during their prime working years and symptoms can be complex and varied
- There is a need for a contextualized understanding of the costs of this chronic disease

Purpose

- To explore and contextualize the direct *and* indirect costs incurred by Canadian patients with SLE
- Conducted in partnership with the Lupus Society of Alberta

Methods

Data Collection

- Semi structured in-depth interviews were conducted via phone with key informants and SLE patients across Canada:
 - 3 expert physicians
 - 5 representatives from patient advocacy groups
 - 28 adult SLE patients (26 female)
- Interview guide focused on direct and indirect costs as well as perceptions, experiences and coping mechanisms

Analysis

- Interviews were audio recorded with permission and transcribed verbatim
- Transcripts were coded both inductively and deductively for recurring themes

Results

Changed career trajectories

- Part-time
- Precarious
- Leaving the workforce all together

“I could maybe do [full-time work] for a month or two, but after that I would crash, and I would probably end up in the hospital again”
(Patient 12)

“It’s not at all covered by [the provincial health plan]. With insurance, you have to cough up the cash first, and it’s not covered a hundred percent. I’ve spent thousands, thousands on physiotherapy”
(Patient 07)

“People just don’t understand, even if they act like it. I have frustration, mixed feelings about sharing it. After all it’s not the big ‘C’ word”
(Patient 21)

Out-of-pocket expenses for health needs

- Pharmaceuticals
- Complementary care (e.g. massage therapy)

Poor public knowledge and understanding of SLE

- Primary reason for not disclosing diagnosis in the work setting

“Because I was so sick I ended up leaving my employment, but by doing so I compromised my pension”
(Patient 04)

Varied use and success with workplace accommodations

- e.g. Working from home, flexible hours, flexible tasks

Poor support in national, provincial policies

- e.g. Delayed diagnosis due to poor access to specialists hinders workplace accommodations
- e.g. Requested greater flexibility in accessing the Canadian Pension Plan (CPP), workplace pensions
- e.g. Requested policies that recognize the ‘flares’ (temporary disability) common with SLE

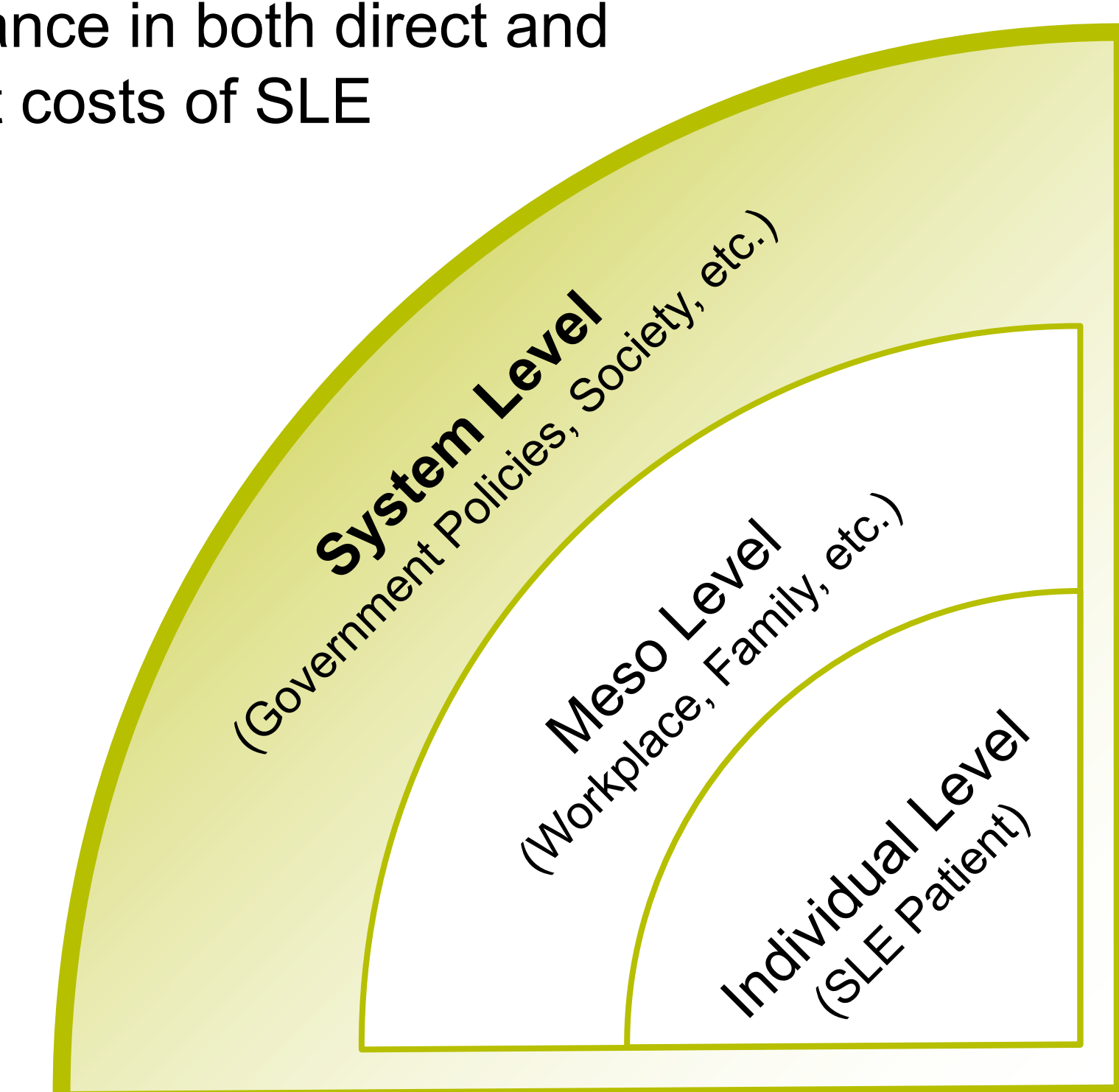
Conclusion

Discussion

- The appearance of the disease during prime working years shifted many SLE participants to “go down a different path” in their lives – one which was less financially stable
- Lack of insurance coverage and increased costs towards health were a financial burden
- Poor public understanding of the disease and mixed success with accommodation impacted workforce participation
- Participants asserted the need for higher-level policy changes to health care access, pensions and disability policies which would ease the financial costs associated with SLE

Take Away Message

- System level factors are of paramount importance in both direct and indirect costs of SLE



Future Directions

- Future work should partner with SLE patients and advocates for programs that address both direct and indirect costs of the disease at the system level

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