“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:
  o 3 expert physicians
  o 5 representatives from patient advocacy groups
  o 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)

Out-of-pocket expenses for health needs
- Pharmaceuticals
- Complementary care (e.g. massage therapy)

“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)

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

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

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

Outcomes in Rheumatology Care

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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