

CREATING A FUNCTIONAL PROFILE OF WORK PARTICIPATION AND ENGAGEMENT NEEDS OF PATIENTS WITH SYSTEMATIC LUPUS ERYTHEMATOSUS TRANSITIONING OUT OF THE COVID-19 PANDEMIC: A NATIONAL QUALITATIVE STUDY

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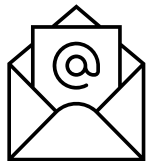
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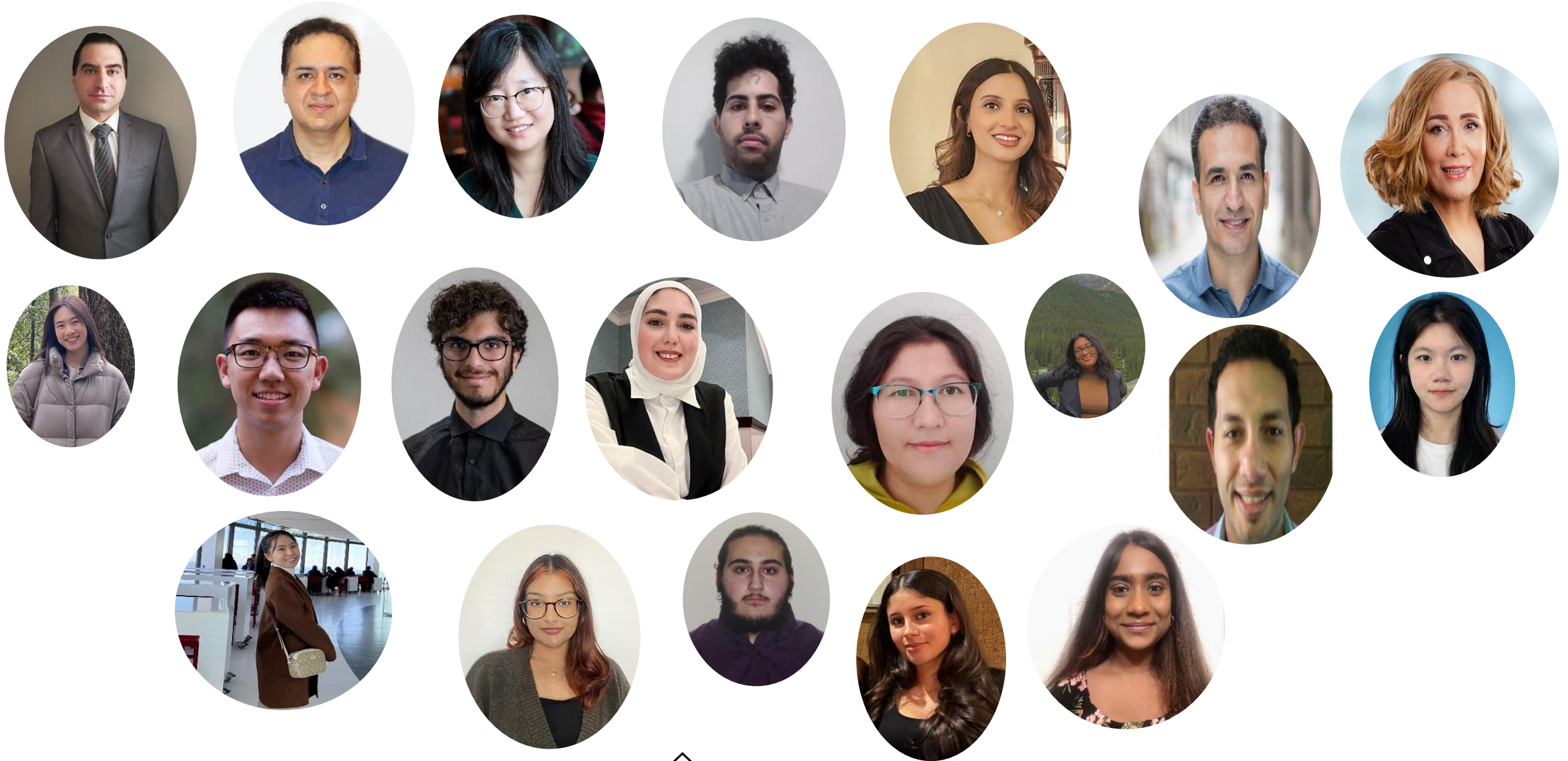
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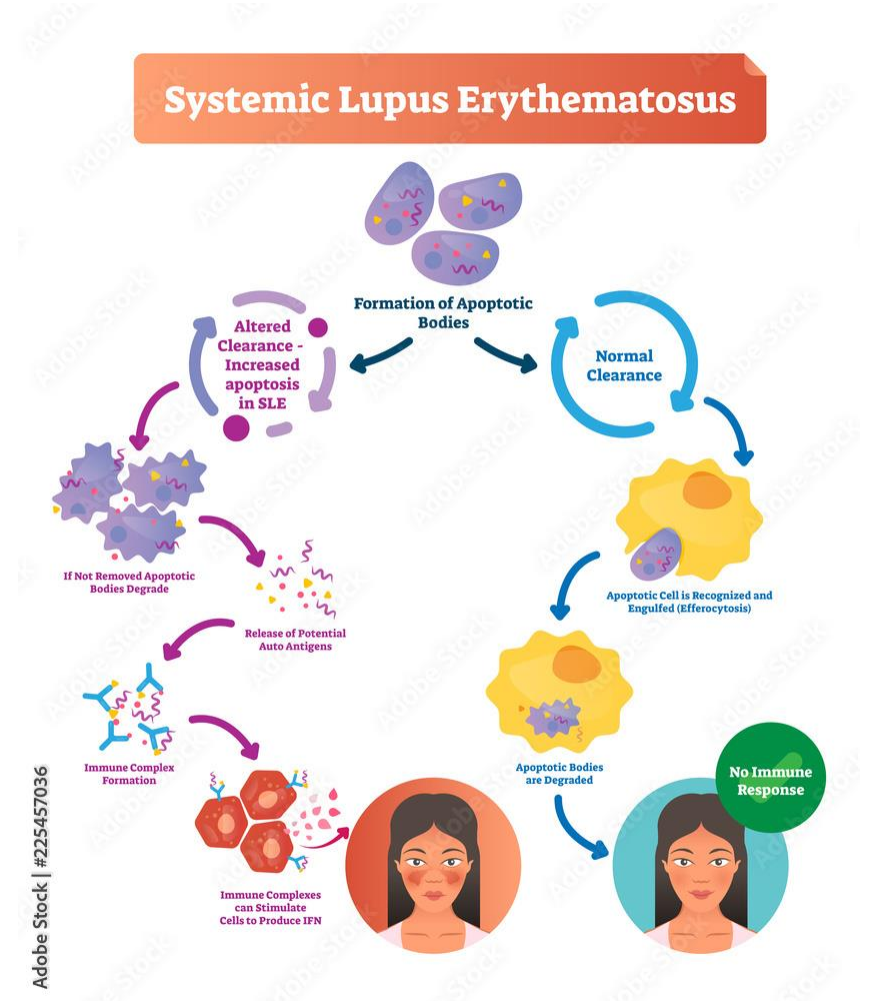




INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic and multisystemic autoimmune disease

SLE can cause mental and physical functional impairments that affect productivity at work and quality of life that may result in work disability (WD)¹

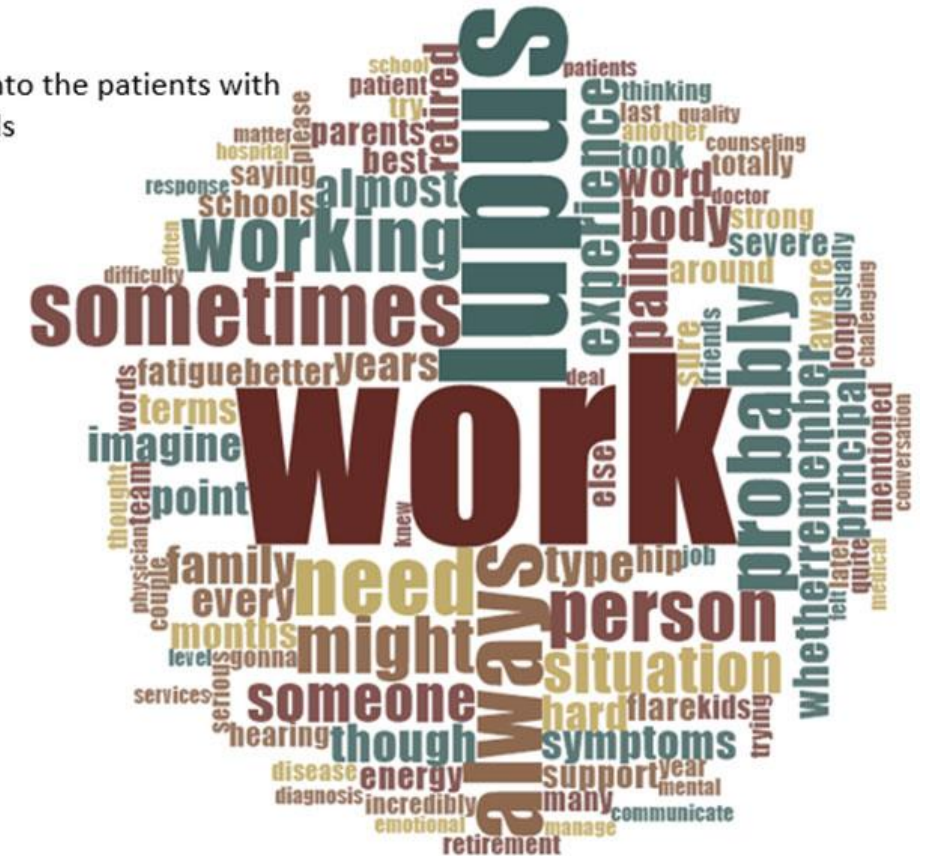


INTRODUCTION

Work disability (WD) arises when an individual is incapable to fulfill their job duties, ultimately leading to inability to work, early retirement, sick leave, a change in work hours or responsibilities, and/or a need for work accommodations²

A recent systematic review suggests that 32.5% of persons with SLE experience some form of WD³

FIGURE 1
An insight into
Lupus' minds



OBJECTIVE

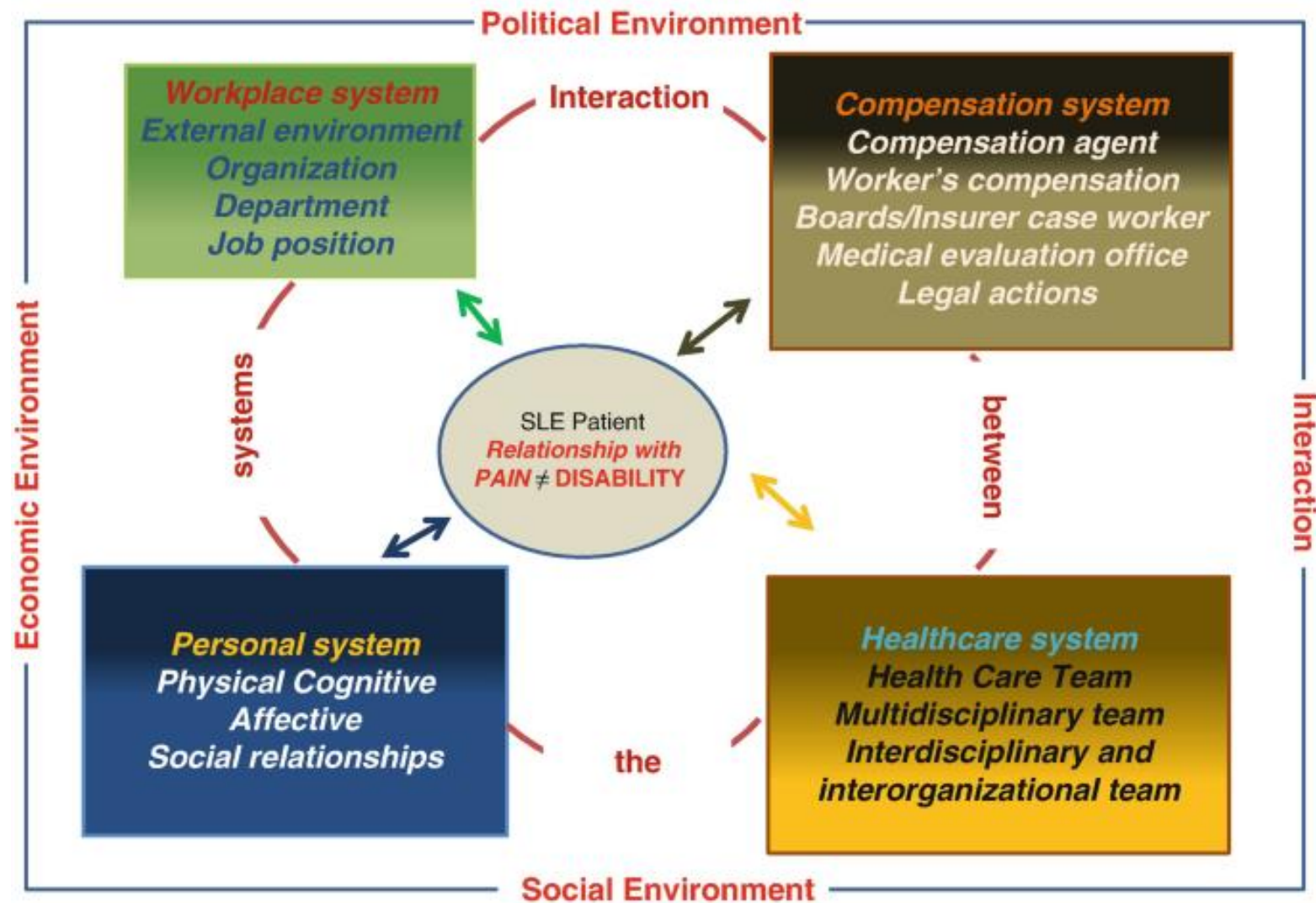
This study explores the roles and interactions between an SLE patient's workplace, healthcare, personal, and compensation systems, in contributing to and mitigating WD.

METHODOLOGY

All participants were seen during regular visits to 12 national rheumatology centres (11 teaching hospitals and one community centre) and were approached to take part in a semi-structured research interview

Eligible participants met the ACR classification revised criteria⁴ or the EULAR/ACR classification criteria SLE⁵, and were between the ages of 18-65

Braun and Clarke six-stage inductive thematic analysis⁶ utilizing the work disability prevention framework



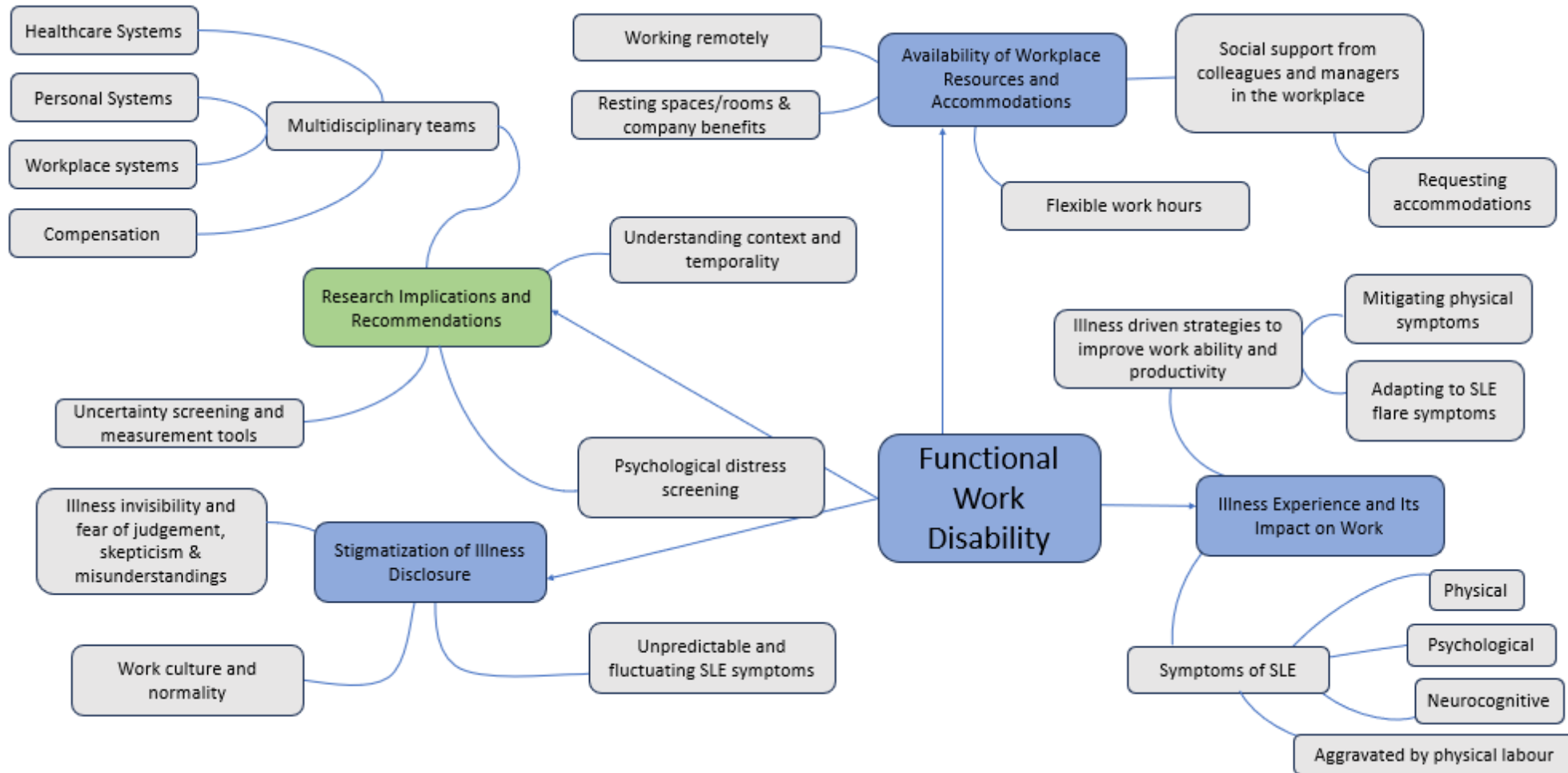
Nowrouzi-Kia, B. and Touma, Z
 Work Disability and Prevention
 in SLE: A Focus on Assessment
 and Function (2021).

FINDINGS – Sample Characteristics

46 semi-structured interviews completed from July 2021 - 2023
(91% female, $M_{\text{age}} = 45.3$, $M_{\text{SLEDAI}} = 3.5$, $M_{\text{SDI}} = 1.1$, $M_{\text{prednisone}} = 7 \text{ mg/d}$)

Most common workplace accommodations:

1. Flexible schedule/breaks (51.4%)
2. Physical assistive aids (29.4%)
3. Increased time away from work (19.3%)



FINDINGS – Disability Discrimination

P1742: “When I worked for the architecture firm, I did hide it at the beginning from the majority of people. I didn't want them to think that I am incompetent because of an illness, and so once I was able to prove and had validation that my work was good, then I was more open about it... Well, in the eyes of society, I have proven that I can function, you know. It's the same as if you're a visible minority, but there's this feeling like you need to prove yourself, but once you've proven yourself, then it's okay to be whatever. It's not right, but I think many people feel like that.”

SELECTED FINDINGS – IMPACT OF COVID-19

Transition from in-person to virtual workspaces:

- Improved health through less exposure to viruses
- Increased presenteeism (“working during symptom flare”)
- Reduced work-life balance
- Involuntary and voluntary job loss as unable to accommodate virtual work

Those who remained in-person:

- Failure to accommodate disability needs
- Public health concerns (e.g. lack of sanitization protocols)
- Increased illness and absenteeism
- Job layoff

FINDINGS - IMPACT OF COVID-19

P110001: “During COVID as you know as a compromised person, it was difficult. As much as I think I would appreciate being in the workplace as opposed to now being self-employed. I just don't. I I don't feel comfortable with that right now. I don't feel comfortable in the university setting teaching. The students [might] have COVID and I am anxious about getting sick [being immunocompromised].”

FINDINGS - IMPACT OF COVID-19

P5002: “I had a lot of brain fog from COVID and I was still coughing and getting exhausted. I was still working and pushing myself to do more than what I should have. I definitely burned myself out and then my flare happened. I was not able return to work after.”

CONCLUSION

Possible WD prevention interventions (Williams-Whitt et al. 2016):

- Identification and modifications of work design, workplace or equipment, or work conditions
- Direct case management support with the worker and supervisor
- External rehabilitation supports for ADL & IADL management and supports outside of the workplace, including navigation through health service, worker's compensation, and disability management systems may also be helpful
- Multidisciplinary team approach: medical providers (especially rheumatologists with expertise on SLE), occupational therapists assess and provide treatment to support return to work
- **Nowrouzi-Kia, B.**, Howe, A., Li, A., Tan, Jeremy., *Saade-Cleves, N., *Jules, K., Sadek, M., Bani-Fatemi, A., Avina-Zubieta, A., Fox, M. T., Shaw, W., Haaland, D., Pope, J., Fortin, P., Bingham, K., Peschken, C., Reynolds, J., Ivory, C., Gladman, D. D., Urowitz, M. B., Sanchez Guerrero J., Lim, L. S. H., Keeling, S., Katz, P., Kavkan, M., Bonilla, D., *Nielsen, W., Touma, Z. (2024). Functional Work Disability from the Perspectives of Persons with Systemic Lupus Erythematosus: A Qualitative Thematic Analysis. *Arthritis Care & Research*. (Under review)

REFERENCES

1. Pisoni CN, Muñoz SA, Tamborenea MN, Garcia M, Curti A, Cappuccio A, et al. (2018) Work disability in Argentinian patients with systemic lupus erythematosus is prevalent and it is due to ethnic, socioeconomic and disease-related factors. *International Journal of Rheumatic Diseases* 21(11): 2019–2027.
2. Ward MM (2013) Chapter 55 - Socioeconomic and Disability Aspects. In: Wallace DJ and Hahn BH (eds) *Dubois' Lupus Erythematosus and Related Syndromes* (Eighth Edition). Philadelphia: W.B. Saunders, pp. 653–658. Available at: <https://www.sciencedirect.com/science/article/pii/B9781437718935000558> (accessed 26 January 2024).
3. Amaral B, Murphy G, Ioannou Y, and Isenberg DA (2014) A comparison of the outcome of adolescent and adult-onset systemic lupus erythematosus. *Rheumatology* 53(6): 1130–1135.
4. Hochberg MC (1997) Updating the American college of rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis & Rheumatism* 40(9): 1725–1725.
5. Aringer M, Costenbader KH, Daikh DI, Brinks R, Mosca M, Ramsey-Goldman, et al. (2019) 2019 EULAR/ACR Classification Criteria for Systemic Lupus Erythematosus. *Annals of the Rheumatic Diseases* 78(9): 1151-1159.
6. Braun V, Clarke V, (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2). United Kingdom: Hodder Arnold: 77–101.
7. Williams-Whitt K, Bültmann U, Amick B, Munir F, Tveito TH, Anema JR, et al. (2016) Workplace interventions to prevent disability from both the scientific and practice perspectives: A comparison of scientific literature, grey literature and stakeholder observations. *Journal of Occupational Rehabilitation* 26(4): 417–433.