

"I'm not living my normal everyday life like I was before:"



Canadians' Experiences with Biographical Disruptions due to Long COVID

Wasilewski, M.B.;Leighton, J.; Reis, L.; Vijayakumar, A.; Sheppard, C.; Nelson, M.; Hitzig, S.; Robinson, L.; Steinberg, R.; Nguyen, M.; Bayley, M.; Chan, A.; Daneman, N.; Ho, C.; Levy, C.; O'Connell, P.; Goulding, S.; Simpson, R.

St. John's Rehab, Sunnybrook Research Institute; Department of OS&OT, U of T; Rehabilitation Sciences Institute, U of T; Division t of PM&R, U of T

BACKGROUND:

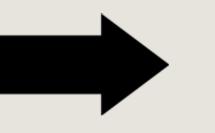
- Evidence suggests 10-35% of people who contract COVID will develop 'long COVID' (LC) (symptoms for 12+ weeks)
- People with LC (PWLC) and their caregivers (CGs) face widespread challenges including disruption to their daily lives and uncertainty about their future but the full scope of this has not yet been investigated
- RESEARCH GAP: Only two studies have begun to elucidate biographical disruptions in the context of LC, with one having a small sample and neither including CG perspectives.

OBJECTIVE

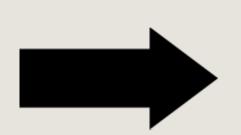
• To explore how PWLC and CGs describe biographical disruptions, their impact on their health and well-being and how they adapt to them.

DATA COLLECTION:

- Qualitative descriptive approach
- Interviews with PWLC (n=52) and CGs (n=15)
- Thematic analysis







LOSS OF MEANING AND PURPOSE

"if I were to die right now, I really wouldn't mind. I think [death] has got to be better than this." (PWLC18)

LOSS OF IDENTITY AND PERSONHOOD

"[it's] a huge emotional toll itself, because all of a sudden, it's that real concrete realization that my livelihood has gone" (CG10)

LOSS OF INDEPENDENCE AND AGENCY

"I can't even go cut the lawn...water the flowers, I used to do all that, I can't do that anymore. " (PWLC48)

RESULTS:

- THEME 1: Disruptions in PWLC and CGs' personal biographies are characterized by a deviation from 'normalcy'
 - PWLC and CGs could no longer perform prior roles or responsibilities and longed for their 'prior lives'
 - Participants recognized their lives needed to take on a new path because 'going back to normal' was not an option
- THEME 2: Biographical disruptions lead to substantial loss and grief
 - Participants described many losses including loss of independence, identity/personhood and meaning and purpose in life
 - This was especially felt with regard to employment and relationship dynamics
 - PWLC did not want to be dependent and felt like they were vanishing
- THEME 3: PWLC and CGs navigate biographical disruptions by adapting daily activities and re-envisioning their roles and responsibilities
 - Participants adjusted their activities of daily living such that they could manage and navigate long COVID's impact on their physical as well as mental health and cognition
 - CGs put themselves on the 'back burner' when overwhelmed by new roles and responsibilities

DISCUSSION:

- Psychosocial support strategies should help mitigate PWLC and CGs' loss and grief stemming from disruptions in envisioned future
 - Accepting and managing LC; Finding hope and motivation for future
- Caregiver-specific support is needed to help them manage their new role
 - Combination of social, emotional and practical supports



For more information, or to connect regarding this project, please email: Jaylyn Leighton, PhD at jaylyn.leighton@sunnybrook.ca