

“I’m not living my normal everyday life like I was before:”

Canadians’ Experiences with Biographical Disruptions due to Long COVID

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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

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



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)

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:

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