

# “Floundering upon the Rocky Shores of Choice”: Paid and Unpaid Caregiver Experiences Accessing Information About Long COVID

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This study investigates the experiences and support needs of paid and unpaid caregivers of those with Long COVID, as well as how they seek information on delivering such care. We carried out individual interviews (n=17) and focus groups (n=3).

## Aims

1. Understand the experiences of paid and unpaid caregivers for those with Long COVID
2. Identify information gaps among those providing care for people with Long COVID
3. Describe information seeking behaviours
4. Identify priority research gaps to facilitate community-driven research in BC and Canada

## Methods

We recruited participants through the 'BC Covid Longhaulers' Facebook group, the Post-Covid Interdisciplinary Clinical Care Network, Family Caregivers of BC, and REACH BC platform. Individual semi-structured interviews (n=17) and focus groups (n=3) were conducted over Zoom with unpaid caregivers (n=8) and paid care providers (n=9). Interview transcriptions were analyzed via emergent thematic coding.

## Results

Caregivers faced barriers such as contradictory knowledge between the Post-Covid Recovery Clinics (PCRC) and General Practitioners (GPs), a lack of concrete knowledge for creating recovery programs, as well as policy barriers impeding disability/financial applications. Misinformation was often a hurdle in delivery of care. Perceptions of care also changed over the course of the pandemic as the PCRC transitioned to a centralized online platform, with patients and Allied Health practitioners being left behind.

Caregivers recommended increasing funding for programs and treatments, developing a long-term plan for Long COVID, reaching out to vulnerable populations, improving societal supports for disabled persons, creating a centralized web portal as a resource for specialists to share information, raising provincial awareness, conducting trials/studies, and reducing medical gaslighting by validating patient experiences.

## Conclusion

Our findings indicate that caregivers of Long COVID patients are experiencing “exhausting” circumstances due to a lack of supports - particularly in financial and medical contexts. Priority research gaps point towards improving information accessibility for caregivers.

## Impacts

Increased labour/Domestic care; Reduced income; Changed relationship dynamics; Impacts on patients

## Barriers

Lack of definitive answers; Inaccessible information/language; Medical gaslighting; Lack of time

## Supports

[Lack of supports]: Mental health & counselling, Household tasks; Financial assistance; Systemic healthcare supports

## Information

Time-consuming; Navigating misinformation; Identifying reliable sources

## Future Care

Increased funding and consistency for programs; Ongoing knowledge base; Increasing awareness

"It's hard when it is Long Covid and we don't have a lot of information because I always get questions of 'When will it be over? Do you think this will be forever?' And I always have to say, 'I don't know. I'm sorry.'"



## Policy Recommendations

One aim of this study was to identify priority research gaps as well as barriers to care in order to improve supports for caregivers of Long COVID patients. Based on our findings, we recommend improving access to information for paid and unpaid caregivers by creating a centralized online resource for information and information sharing. Prioritizing long-term strategies and healthcare pathways for Long COVID patients will also benefit caregivers. Education of GPs to reduce and remove medical gaslighting to validate patients and therefore access to financial assistance or disability applications will in turn support caregivers that are balancing increased domestic responsibilities and adverse economic impacts.