

Long COVID information-seeking experiences: Considerations to improve access to information and care

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This study interviewed a cohort (n=30) of Long COVID patients in British Columbia (BC) to explore how they sought information on the management of Long COVID symptoms, the support (or lack) they received in clinical and social contexts, and the socioeconomic impact their symptoms have made on their lifestyles and relationships.

Aims

1. Identify **information-seeking experiences** of Long COVID patients in clinical/online settings
2. Assess any **needs and lacking supports** to indicate pathways for future research priorities investigating the impacts of Long COVID across Canada

Methods

We recruited participants through the 'BC Covid Longhaulers' Facebook group, the Post-Covid Interdisciplinary Clinical Care Network, and REACH BC platform. **Individual semi-structured interviews** were conducted over Zoom with patients (n=30) who self-identified as experiencing Post-Covid symptoms. Interviews were qualitatively analyzed via **emergent thematic coding**.

Results

We found that Long COVID patients face a number of challenges accessing information relevant to their care. Most notably patients faced **medical gaslighting** when seeking healthcare, and a lack of supports to address new disabilities and subsequent **financial, social, and mental stresses**. We found that patients were motivated to join **online communities** as access to symptom management information in clinical contexts was fraught with gaslighting, medical misinformation, or a lack of information. Conversely, reliance on social media sources require patients to navigate misinformation and balance the influx of **too much information** that may strain symptoms due to cognitive difficulties and fatigue. Patients also described **mixed experiences** when accessing care at the **provincial Post-COVID Recovery Clinics**, with usefulness of information varying considerably.

Conclusion

Our findings indicate significant **room for improvement for making Long COVID information more accessible to patients** in BC. Patients have provided recommendations for addressing these gaps in care, notably by suggesting increased **education for General Practitioners** and by creating a **centralized place for up-to-date Long COVID information**.

Impacts

Labour; Health; Family members; Lifestyle;
Economic security; Perception of self

Coping Strategies

Physical; Mental; Social

Supports

Lack of supports; Access to health services;
Social supports; Economic supports

Information

Usefulness; Relevance; Accessibility;
Trust; Sources

Lived Experiences of Policies

Return-to-Work; Referrals; Long COVID
Clinics; Lifting of Protections

Emotions

Resilience; Anxiety; Shame; Fear

Care

Health-system provided vs Self-directed;
Useful vs Not Useful

Relationships

With partner; Immediate family; Extended family;
Friends; Care provider; Colleagues; Employer

Invisible Illness

Gaslighting; Comparisons to other illnesses;
Assumptions by others

Recommendations/Gaps Identified



"I just think that there's like a real lack of public awareness which is further stigmatizing."

Policy Recommendations

Patients have identified that **policy barriers significantly impeded access to care** and recovery. These have included **return-to-work programs** hosted by work insurance companies rushing patient recovery and consequently worsening symptoms. We recommend **investing significant funding into provincial Long COVID care**, as well as **educating Physicians and relevant stakeholders** of this condition to minimize medical gaslighting, stigmatization, and prolonged recovery time.