

Long COVID and self-management

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The Lancet

Long COVID and self-management – we need to know the benefits and the harms --Manuscript Draft--

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Author Comments:	<p>We would like to submit a letter to The Lancet discussing self-management of Long COVID symptoms with over-the-counter (OTC) medication, alternative remedies and other therapies.</p> <p>Anecdotal evidence suggests market access issues in healthcare, and lack of available treatment options and support are driving many Long COVID survivors to take matters into their own hands by resorting to self-management practices that lack an evidentiary base. The current lack of adequate support and treatment can be partly attributed to the early and evolving understanding of the condition's sequelae.</p> <p>Self-prescription carries with it many potentially harmful side effects, including negative drug-drug interactions. Given the high prevalence of Long COVID, it is important to understand how individuals are managing their symptoms to identify potential harms as well as benefits.</p> <p>Our letter calls for further research into this important and widespread matter. We aim to increase awareness among the medical and scientific community on the issue of non-prescribed therapies in the context of Long COVID in order to spur research in this area to improve clinical care and the quality of life of patients.</p>

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Corresponding author: Kirsty Brown

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Authors contributions:

KB, AY, JC and GT contributed to the conception of the letter. KB conducted literature searches and drafted the manuscript with supervision from SH and GT. AY, SH, JC and GT provided feedback on the manuscript. All authors read and approved the final manuscript.

Covering Letter (200 words):

We would like to submit a letter to The Lancet discussing self-management of Long COVID symptoms with over-the-counter (OTC) medication, alternative remedies and other therapies.

Anecdotal evidence suggests market access issues in healthcare, and lack of available treatment options and support are driving many Long COVID survivors to take matters into their own hands by resorting to self-management practices that lack an evidentiary base. The current lack of adequate support and treatment can be partly attributed to the early and evolving understanding of the condition's sequelae.

Self-prescription carries with it many potentially harmful side effects, including negative drug-drug interactions. Given the high prevalence of Long COVID, it is important to understand how individuals are managing their symptoms to identify potential harms as well as benefits.

Our letter calls for further research into this important and widespread matter. We aim to increase awareness among the medical and scientific community on the issue of non-prescribed therapies in the context of Long COVID in order to spur research in this area to improve clinical care and the quality of life of patients.

Acknowledgments:

Issues and concerns around self-management of Long-COVID symptoms were highlighted by our patient partners. Our letter has been informed by their own experiences and knowledge and insight from Long COVID support groups, forums and peer support.

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Long COVID and self-management – we need to know the benefits and the harms

People with COVID-19 often experience longer-term symptoms (Long COVID), including fatigue, breathlessness, and neurocognitive difficulties.¹ The disease mechanisms causing Long COVID are unknown, and there are currently no evidence-based treatment options. Clinical guidelines focus on symptom management, while various treatment options are being evaluated.¹ The lack of advice has frequently left people with Long COVID feeling isolated and frustrated in their search for therapies.

Studies found a wide range of self-prescribed medications being used for prevention and management of acute-COVID-19, including antiretrovirals, penicillin, vitamin C, traditional medicines, and chloroquine/hydroxychloroquine.^{2,3,4} Self-prescribing practices are unsurprising given the high incidence and mortality from COVID-19, restricted access to healthcare during lockdowns, and limited treatment and preventative therapies for COVID-19.

There is a lack of research on self-management practices among individuals with Long COVID. Anecdotally, patients and patient advocacy groups have reported a lack of timely support and poor recognition of Long COVID, partly attributable to lack of knowledge and evidence of Long COVID, and overwhelmed healthcare systems. This has led to loss of faith and disappointment in healthcare service delivery, leading Long COVID sufferers to seek alternative sources of support and treatment.

Long COVID sufferers reported turning to a vast range of over-the-counter medicines, remedies, supplements, other therapies, and dietary changes to manage relapsing and remitting symptoms. Individuals have expressed a willingness to try anything because symptoms have significant impacts on quality of life and work capability.

There are potential risks of self-prescription, such as harmful drug-drug interactions and use of inappropriate treatments.⁵ Medicines may be used off label, in unsafe doses and sometimes purchased in an unregulated manner overseas. Harmful drug-drug interactions are enhanced due to the complexity and multiple symptoms of Long COVID leading to use of multiple treatments.

Long COVID sufferers have sought advice from social media platforms such as Facebook where individuals share their self-management experiences, and online resources, including medical blogs and journals. Due to the limited evidence base, these are a potential source of conflicting information and misinformation.

Self-management of long-term symptoms are often extremely costly, with some individuals using a significant proportion of their income, which threatens to widen existing health inequalities. Further inequalities include geographical disparities in access to Long COVID clinics; access to private healthcare; and health literacy.

Research is needed to understand the self-management practices being used to manage Long COVID symptoms, factors influencing their uptake, and the benefits, harms, and costs. There is also a need to assess the potential harmful effects of polypharmacy and drug-drug interactions in these individuals.

The Therapies for Long COVID (TLC) Study will explore this through a survey of those living with Long COVID. This aims to be a first step towards understanding this important and under-researched public health issue.

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