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Long COVID and self-management

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

Studies have reported a wide range of self-prescribed medications being used for prevention and management of acute COVID-19, including anti-retrovirals, penicillin, vitamin C, traditional medicines, and chloroquine or hydroxychloroquine.²⁻⁴ Self-prescribing practices are unsurprising given the high incidence of and mortality from COVID-19, restricted access to health care during lockdowns, and few treatments and preventive therapies for COVID-19.

There is an absence of research on self-management practices among individuals with long COVID. Patients and patient advocacy groups have reported an absence of timely support and poor recognition of long COVID, partly attributable to insufficient knowledge and evidence of long COVID and overwhelmed health-care systems. Insufficient support has led to loss of faith and disappointment in health-care service delivery, leading people with long COVID to seek alternative sources of support and treatment.

People with long COVID 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 substantial effects 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 can 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.

People with long COVID 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 small evidence base, these platforms are a potential source of conflicting information and misinformation.

Self-management of symptoms in the long term is often costly, with some individuals using a substantial proportion of their income, which threatens to widen existing health inequalities. Further inequalities include geographical disparities in access to clinics for long COVID, access to private health care, and health literacy.

Research is needed to understand the self-management practices that are 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 (ISRCTN15674970) will begin to explore self-management practices through a survey of people with long COVID. This study aims to be a first step towards understanding this important and under-researched public health issue.

JC has participated in Patient Public Involvement for University College London and University Hospitals Bristol. JC has been a National Institute for Health and Care Excellence Covid Expert Panel lay member and a patient representative for other boards and organisations in the UK and Europe. JC has also been a received honorarium from GlaxoSmithKlein for

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Intersectionality and developing evidence-based policy

It is reassuring to see that ministers in the UK are formally acknowledging how people from minority ethnic (ie, defined here as all ethnicities other than White British) backgrounds have been disproportionately affected by COVID-19. However, crucial gaps exist in the collection, analysis, and translation of data to assess the effects of multiple intersecting factors on individuals and communities. The Science and Technology Committee and Health and Social Care Committee report, *Coronavirus: lessons learned to date*,¹ dedicates thirteen paragraphs to



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