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COVID-19

Patient commentary: How power imbalances in the narratives, research, and publications around long covid can harm patients

Amali Lokugamage and colleagues argue that patients are still struggling to get their voices heard above doctors, a situation that risks “structural iatrogenesis”

Amali U Lokugamage,¹ Frances K Simpson,² Carolyn A Chew-Graham^{3,4}

Social media platforms have brought together thousands of people with long covid, allowing them to discuss, share, and compare their experiences of relapsing and remitting symptoms.¹ This phenomenon has disrupted and flattened traditional power structures, where doctors were always the experts and patients’ opinions were less valid. But power imbalances remain, especially in the creation of health knowledge, where prominent names in medicine seem to get easy access to the media—leaving less well resourced lay people who are affected by long covid feeling aggrieved and disempowered.

Several research papers describe abnormalities confirming pathophysiological damage ranging from abnormal blood tests to organ damage seen on MRI imaging or in postmortem findings.^{2–4} These publications run counter to the tendency among many doctors to put long covid symptoms down to anxiety or to attribute other psychological labels, which then allows them to avoid investigating symptoms to look for organic pathology.¹ Organic disease processes are clearly at work.^{5–8} This has been recognised by recent interim guidance from the US Centers for Disease Control on managing people with long covid.⁹

We don’t deny that all symptoms will have a psychological impact on the individual, and we would not wish psychological impacts to be stigmatised or ignored, but organic illness must be investigated and should be excluded only after appropriate investigation.¹ People with long covid describe feeling “gaslighted” because the opinions of a few have tended to dominate the evolution of treatment, investigation, and a growing knowledge base.¹

We believe that this is a form of “structural iatrogenesis,” where patients are harmed by power imbalances in the bureaucratic and cultural systems within medicine.¹⁰ Narratives on social media reveal that research produced by patients themselves has encountered more obstacles to publication, with journals claiming that it comes from the “wrong sort of expert.”^{11–13}

Twitter and other social media are correcting this imbalance, although the results aren’t always pleasant. Behind the Twitter “spats” are thousands of individual patients with long covid who believe that advocating for graded exercise therapy rather than pacing to manage fatigue in long covid may lead

to management regimens that make symptoms worse.¹⁴

Knowledge production in this new condition of long covid must therefore involve and engage patients and the public, not only to ensure co-production of knowledge but also to avoid top-down hierarchical service provision, which may make logical sense to people who have never experienced the condition but will be totally inappropriate to those affected by long covid.

Ultimately, toppling endemic power imbalances in medicine requires the input of people who have experienced the cognitive dissonance of confronting personal and healthcare structural biases, so that those providing healthcare fully comprehend the lived realities of the individuals they seek to serve. This is work that cannot be avoided.

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