Long covid clinics should be run as research hubs

Multidisciplinary care is not magically beneficial and can exclude patients from decisions

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The current and future effect of long covid—which includes both ongoing symptomatic covid-19 (4-12 weeks) and post-covid syndrome (after 12 weeks)—remains a staple in the media. A network of new clinics has been pledged in England amid widespread concern that many people have enduring symptoms. The National Institute for Health and Care Excellence (NICE) indicates that most people will recover,1 but also recommends that clinicians “consider referral” to “an integrated multidisciplinary assessment service” if people still have symptoms after four weeks.1 Is this the best way forward? We believe that substantial investment in specialist services to manage ongoing symptoms should proceed only under high quality research conditions.

Post-covid syndrome is unlikely to be a single entity and will vary according to whether people required invasive hospital treatment. There is probably a spectrum of underlying pathology, including self-limiting inflammation and damage to specific organs, continued viral presence, the sequelae of intensive care admission, autoimmune responses, and more general disruption of immune, inflammatory, endocrine, and neurological systems (comparisons have been made with chronic fatigue syndrome (CFS/ME)).1 Perspective is gained by considering what we know about recovery and rehabilitation after other serious infectious illnesses and our knowledge about the harms and benefits of diagnosis, treatment, and multidisciplinary teams.

The April 2021 survey by the Office for National Statistics shows 21% of people with confirmed covid-19 still have symptoms at 5 weeks and 13.7% at 12 weeks.4 A recent population based longitudinal study from Australia reported high rates of recovery among adults with confirmed covid-19 (20%, 80%, 93%, and 96% at 10, 30, 90, and 120 days respectively).5 This indicates that, however distressing the symptoms, most people meeting NICE criteria for long covid are on a path, albeit often fluctuating, to natural recovery.

The figures for other infectious illnesses are comparable. For example, people aged over 50 with community acquired pneumonia report feeling breathless and weak for an average of 22 days and 24 days respectively; those with chronic obstructive pulmonary disease took an average of 52 days to recover, meaning that about half took longer.6 More than a third of low risk, ambulatory patients with community acquired pneumonia are still symptomatic 28 days later.7 Comparison between post-covid syndrome and CFS/ME is difficult as studies of CFS/ME commonly start with populations who have had symptoms for many months or years, but most show low rates of recovery.8

Concerns have been raised about enduring organ damage caused by covid-19, with some cardiac imaging studies of people who have recovered from covid-19 finding high rates of myocardial9 and organ inflammation.10 However, significantly disordered inflammatory response was found in those with and without symptoms, indicating a prolonged but not necessarily pathological response.11 Some studies suggest that myocarditis is relatively common after seasonal influenza,12 and 40-50% of patients admitted to intensive care with H1N1 associated acute respiratory distress syndrome reported exertional dyspnoea one year after discharge.13 Rather than seeing long covid as a new disease or set of syndromes, we could consider it in the context of problems seen routinely in general practice after infections or trauma—disrupting our ability to withstand stressors in an undifferentiated way, with unclear aetiology or prognosis, but nevertheless likely to resolve spontaneously. The value of investigation or drug treatment remains unclear and is likely to be limited.

Clinical services, often including multidisciplinary teams, are being set up to treat patients with ongoing symptoms from covid-19. They have been generally welcomed, but critical evaluation is important to ensure they serve patients well. Multidisciplinary care is not magically beneficial, is resource intensive, and can exclude patients from decisions. Timely use of the skills and knowledge of different specialist professionals is helpful, but improved decisions require an evidence base showing meaningful benefit for patients and cost effectiveness.

Without this evidence, there is the potential for harm through routine imaging and associated overdiagnosis, ineffective or harmful treatment, and wastage of resources through duplication of effort.14 Inconsistent advice is also a danger: without evidence based interventions people attending new clinics may be no better off, and may be worse off.

Despite this, there are no plans for these new services to be run as research hubs or be formally evaluated—a missed opportunity given the excellence achieved in drug treatment trials for covid-19. It may be that primary care could be resourced to deliver timely expert generalist care and social support more effectively than the multidisciplinary clinics. Assumptions about the benefit of new clinics, rather than critical evaluation and in-practice research, is likely to lead to poorer quality interventions and poorer information and support for a worried public.

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