Recognising and bearing the burden of long COVID-related disability

Long COVID is nicely discussed by Burke and del Rio in a short article in *Lancet Infectious Diseases*.¹ The UK is world leading in having two large, high-quality prevalence studies of COVID-19 in the ONS Infection Survey² and REACT³ (but this advantage is thrown away when politicians ignore the findings).

The ONS infection survey has strong design, and estimates 1.3% or 862 000 people with long COVID symptoms persisting for more than 12 weeks, including 0.26% or 177 000 reporting daily activities limited a lot, with 98 000 of these being first infected more than a year ago.² REACT also found a high prevalence of persistent symptoms.³ This represents a large burden of disability for individuals, their supporters, and the economy, with GPs on the frontline. Yes, this is self-reported survey data, but the ONS measure of activity restriction is academically respectable.⁴ Focusing on activity restriction captures severity and impact, and sidesteps issues with symptom lists while long COVID remains poorly understood. Corroboration is required, and, with political will, these numbers could be cross-checked with routine data such as school and work absences in a matter of weeks.

CONTEXT IS HARD TO FIND

Lack of attention to long COVID-related disability has contributed to ineffective and unsafe policy decisions, for example, relating to mitigation in schools. This is perhaps unsurprising given that, with the recent exception of mental health issues in veterans, governments have a long tradition of ignoring disability in those under 65 years. An admittedly selective quote from a government website is telling: the Opinions and Lifestyle Survey 'Collects information on a variety of topics that are too small to have surveys of their own ... including ... climate change and disability.'⁵

Although several government surveys measure limiting, longstanding illness and activity restriction, this remains mostly

unpublished. So, context is hard to find. A rigorous 2011 study of ME/CFS using multiple definitions and methods of ascertainment found English prevalence between 0.03% and 0.2% in those aged 18 to 64 years.⁶ Alternatively, the excess burden of long COVID-related disability may be compared to the 153 158 casualties of all severity in reported road traffic accidents in 2019.⁷

INTEGRATIVE CARE

Families will often have the resources to meet this health challenge, including family and social networks, support groups, and careful use of social media. GPs have important roles of backstop and referral, and continuity of care. There is a concern that many sufferers may slip through the net, or simply fail to present at primary care, because they perceive a COVID-weakened service will be unable to help them.

Without a trusted health professional who can refer and prescribe in their support network, sufferers will be at increased risk of developing longstanding illness or mental health crisis. In tackling this challenge, GPs and other frontline health professionals are developing new models of integrative care from the bottom up, alongside all the other demands on their time. GPs urgently need the breathing space and reinforcements to continue this vital caring and preventive work.

A feature of the pandemic is the thousands

of health professionals and academics in the UK with the experience to see the pandemic coming and what needed to be done. But they were either sidelined (Indie SAGE,⁸ retired health professionals), or too busy just keeping the ship afloat or doing other important work (frontline health workers, health researchers). Perhaps it's time to put some of this energy and pent-up frustration to good use.

Increasingly, the pandemic in the UK looks like a war that's yet to be won. Health and social care services face triple challenges of Omicron, long COVID, and pandemic backlog. Keeping the system and the people in it in some kind of shape through winter 2021 and into 2022 requires new resources and divergent thinking.

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