Long COVID and the importance of the doctor–patient relationship

A pandemic was declared in March 2020, due to a novel virus, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It was initially reported that COVID-19 infection could cause dramatic variation in clinical outcome, from asymptomatic infection through to multi-organ failure and death. Early data reported that 17% of people hospitalised due to COVID-19 would require intensive care, and 32% of these people would die.[1,2] Nationally, and internationally, planning focused on identifying and managing the very sick, and reducing people's exposure to the virus. In primary care, in the UK, there was a move to remote consulting, with the majority of consultations being conducted by telephone or video, and face-to-face consultations being in the minority for the first time in the history of the NHS.[3] The prominence of NHS 111 to differentiate between the 'sick' and 'not sick', and setting up 'hot hubs' for assessment of people suspected of having COVID-19 in the community, changed the face of primary care.[4]

WITNESSING THE EMERGENCE OF A NEW DISEASE

It became clear, however, that the perception that people either die, get admitted to hospital, or recover after 2 weeks was wrong, and that people were continuing to experience persistent symptoms despite apparently mild acute symptoms. Clinicians in primary care, consulting virtually, were hearing narratives from patients who described persistent problems, such as chest pain, palpitations, shortness of breath, fatigue, 'brain fog', odd rashes, and loose stools. People with these symptoms, however, were rarely offered a face-to-face appointment with a GP, often spoke to a number of different GPs, and were distressed to find that GPs were as baffled as they were.[5] Remote consulting added to the delay in recognition that persistent symptoms were not rare. Some people with ongoing symptoms took to the media (mainstream and social) to describe their problems,[6,7] and to raise awareness of persistent symptoms,[8] which came to be labelled as 'long COVID' by patients themselves.[9]

> "[Primary care clinicians were] *witnessing the emergence of a new disease* ... [and] *were initially working in an evidence-free zone* ..."

Primary care clinicians were initially working in an evidence-free zone, but gradually key primary care researchers published helpful guidance,[10] with the National Institute for Health and Care Excellence scoping guidance published in October 2020,[11] and full guidance in December 2020.[12] The latter not using the patient-preferred term 'long-COVID', rather using 'post COVID-19 syndrome', to describe symptoms persisting after 12 weeks. Some people with persisting symptoms were not happy with this new label.[9] A National Institute for Health Research themed review[13] emphasised the fluctuating and multi-system symptoms, and suggested that there was a need for 'one-stop shop' clinics to offer assessment and investigation for people with long COVID.

FINDING THE 'RIGHT' GP

The Royal College of General Practitioners (RCGP) published guidance,[14] which included 'top tips' for clinicians — the first of which emphasised the need for the patient to be believed, that their symptoms are taken seriously and not dismissed as due to 'anxiety', and the importance of finding the 'right' GP.[5] In addition, a possible pathway for investigation and management was outlined. The RCGP also developed an online learning module, made free to non-members, which emphasised the priority the RCGP gives to this topic, and the RCGP presented evidence to the House of Lords report.[15]

The NHS released the 'Your COVID recovery' website (https://www.yourcovidrecovery.nhs.uk) and announced investment in services for people with persisting symptoms.[16] At the time of writing this editorial, we are far from seeing long COVID clinics in every locality. Some people with long COVID, with the financial means to do so, have sought private or complementary therapies.[5,17] Such help-seeking may be the result of people feeling desperate and frustrated that the NHS (and GPs in particular) does not seem able to help.[5]

Management of people with long COVID is the responsibility of general practice. People with persistent symptoms have had to become experts in their symptoms and impact, and GPs may only know as much as their patients can share with them, given the rapidly emerging evidence-base.

IMPORTANCE OF THE DOCTOR–PATIENT RELATIONSHIP

One of the RCGP's current priorities is 'relationship-based care',[18] and the patient–doctor relationship is vital in the management of people with long COVID. GPs need to listen to people with persisting symptoms following acute-COVID infection, offer empathy and support, and most importantly, help them to navigate the developing referral pathways — acknowledging that currently this may involve referrals to different specialties. The GP must support the patient, and their families, in 'putting it all together'.

There have been attempts in the media to link long COVID with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)[19] or post-viral fatigue; however, this linkage has the potential to leave persistent symptoms uninvestigated and may be potentially harmful to patients.[17] Certainly long COVID is currently unexplained, but organic pathology must be excluded before a plan for rehabilitation is suggested to the person living with symptoms.[20] So the questions remain for GPs: 'how am I going to differentiate long COVID from other complex symptoms?', and 'what resources are available for me to refer patients with long COVID to?' There is a need to translate the NICE guidance[12] into services for people with persistent

> "[There is a] *need for the patient* [with long COVID] *to be believed, that their symptoms are taken seriously and not dismissed as due to 'anxiety', and the importance of finding the 'right' GP.*"

symptoms. This will require investment in UK-wide community diagnostics, access to therapies, such as physiotherapy, psychology (including Improving Access to Psychological Therapies services[21]), occupational therapy, and specialist rehabilitation, and organised as an integrated offer for patients. Investment and commitment, however, is also needed by practices to ensure that we can offer continuity of care, recognising the value of the patient–doctor relationship in the delivery of high-quality, safe, care.

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