There is increasing evidence that large numbers of people who have tested positive for Covid-19 develop symptoms – either when they contract the Covid-19 infection or in the following three months – that can last for months or even years (National Institute for Health and Care Research (NIHR), 2020). These symptoms are diverse and include new medical diagnoses, but some are hard to diagnose and are known by the umbrella term ‘long Covid’.

March 2022 saw the two-year anniversary of Covid-19 being declared a global pandemic by the World Health Organization, and since then long Covid has been affecting increasing numbers of people. Thanks to emerging research, we know more about the condition, its symptoms, causes and prognosis, and the nurse’s role, particularly in symptom management.

Many uncertainties around long Covid persist as data has been gathered using different definitions, assumptions, methodologies and means of collection. While there is emerging evidence of the underlying pathology – which will be outlined below – the mechanisms remain unclear, and treatment is limited. However, much can be drawn from knowledge of other diseases.

Prevalence

Estimates of prevalence range widely, and the impact of new variants and improved treatment of acute infections is unknown. While the Zoe app took a single report of one week without symptoms as the end-point, ONS takes two consecutive monthly reports with no symptoms as the endpoint; this equates to a seven-week difference, reflecting that long Covid is a relapsing and remitting disease. Several studies report that symptoms change over time; for example, Tran et al (2022) recently published their follow-up of people with three months or more, and 79,000 had symptoms lasting over a year. Some people were still experiencing life-changing symptoms two years later (ONS, 2022).

Key points

Long Covid is a multisystem condition with a wide range of symptoms and is, for some, a long-term condition

The experiences and presentations of long Covid are complex and there are competing views about what causes them and how to treat them

Many of the physical effects of long Covid are not detectable through routine tests but may be identified with specialist tests

Most people will access help through general healthcare services rather than specialist clinics

Many physical and mental symptoms of long Covid are present in other conditions, so nurses already have expertise in their management

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Abstract

Long Covid is more than a prolonged recovery from a respiratory infection; it is a multisystem, and potentially long-term and life-changing, disease. Many people carry the illness burden, including nurses, who may be disproportionately affected due to their high risk of Covid-19 infection. In this first in a series of three articles on long Covid, we look at what is known about the condition, its symptoms, causes and prognosis, and the nurse’s role, particularly in symptom management.

Citation

Long Covid is an umbrella term and can include a range of well-recognised, but undiagnosed, conditions, as well as being a potentially novel condition in itself (Maxwell, 2021; NIHR, 2020). Patient groups report numerous cases of persistent, unexplained symptoms that are diagnosed a year or more after they first appeared as conditions requiring medical care (Facebook Long Covid Support Group, personal communication, April 2022).

Although evidence is increasing that Covid-19 is a multisystem disease (Maxwell, 2021) attention initially focused on acute respiratory failure. This has framed long Covid as an extended recovery from a respiratory infection, exemplified by the early research funding for the follow-up of hospitalised patients and for general NHS advice through the Your Covid Recovery website (yourcovidrecovery.nhs.uk).

There are people with continuing ill health associated with a Covid-19 infection, however, who do not fit into this rehabilitation model; there are also those with Covid-19 infection confirmed by a PCR test who never experienced breathlessness. As an example, a large study of medical positive polymerase chain reaction (PCR) test experiencing long Covid, who reported their symptoms via an app. As many as 85% still had symptoms one year after onset but, while some symptoms had decreased in frequency, others had increased, and yet more had plateaued. For example, the prevalence of coughing decreased from 50% to 20% in the first six months, before plateauing up to and beyond 12 months.

Continuing symptoms appear higher in people admitted to hospital with Covid-19 (NIHR, 2020), but hospitalisation is not a good predictor of the total number of people with long Covid. ONS (2022) has reported that more than 90% of people with long Covid were never admitted to hospital and around 50% had no NHS contact at all during the acute infection.

Vaccines may reduce the number of new cases of long Covid but will not eliminate them. A rapid evidence review from the UK Health Security Agency (2022) found that even a single vaccination dose can reduce the risk of long Covid. However, the US Department of Veterans Affairs found that, compared with those without a history of Covid-19 infection, people with infections following vaccination have an increased risk of sequelae, with an illness burden of 99 people per 1,000 breakthrough infections (Al-Aly et al, 2021, preprint). They found this risk was higher than in people with seasonal influenza – extending the evidence that Covid-19 is not ‘just flu’.

The hypothesis that a small percentage of a large population equals a large absolute number is pertinent in terms of long Covid. Given the very high infection rates with Omicron – and with one in 12 people in the UK not having had a first vaccine dose, increasing to one in seven for a second dose (UK Government, 2022) – it is reasonable to assume that a large number of people will continue to develop long Covid for some time yet.

Internationally, there is a consensus that long Covid is more common in working-age populations and more prevalent in women (Maxwell, 2021; NIHR, 2020). The ONS (2022) monthly survey in May of more than 340,000 households in the UK showed that 2.4% of healthcare staff reported long Covid symptoms for over a year, which is double the rate in the finance sector. Nurses are, therefore, at significant risk of long Covid.

Symptoms

Long Covid is an umbrella term and can include a range of well-recognised, but undiagnosed, conditions, as well as being a potentially novel condition in itself (Maxwell, 2021; NIHR, 2020). Patient groups report numerous cases of persistent, unexplained symptoms that are diagnosed a year or more after they first appeared as conditions requiring medical care (Facebook Long Covid Support Group, personal communication, April 2022).

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There are people with continuing ill health associated with a Covid-19 infection, however, who do not fit into this rehabilitation model; there are also those with Covid-19 infection confirmed by a PCR test who never experienced breathlessness. As an example, a large study of medical
records found increased prescription of analgesia (including opiates), antidepressants, antihypertensives and oral hypoglycaemics in the six months after confirmed Covid-19 compared with controls (Al- Aly et al, 2021, preprint). A lack of understanding of the evidence means undifferentiated symptoms are not always fully investigated. Two long-Covid services in the UK have reported that patients who were hospitalised and those who were not presented different phenotypes, with those who were not hospitalised referring later and having more pain and breathlessness (Heightman et al 2021; O’Sullivan et al, 2021). It is unclear whether this relates to lack of treatment in the acute phase (for example, steroids), lack of other early intervention or different causal mechanisms.

Pain was the most frequently reported symptom in several studies of medical records; for example, Table 1 gives the ranked frequency of symptoms and how this varied by age group in Fair Health’s (2021) review of 1.9 million insurance claims in the US.

There are reports of a very diverse range of symptoms across all body systems reported in this US study (Fair Health, 2021). This may indicate different causal mechanisms, which may require different treatments. However, the number of symptoms reported is a poor proxy for impact on mechanisms, which may require different first-line diagnostics, such as chest X-rays and computed tomography scans, do not always capture the organ damage caused by Covid-19 (Grist et al, 2022, preprint). Similarly, routine blood tests are often normal (Chen et al, 2021), so nurses should consider referrals for more specialist testing if symptoms persist.

Post-exertional malaise is experienced by many people with long Covid, who have reported that their symptoms are worsened by “pushing through” with exercise (Tomowey et al, 2021, preprint). Post-exertional malaise appears similar to overtraining syndrome. That syndrome sees a reduction in the performance of elite athletes, but Cadegiani and Kater (2019) suggested it would be better to call it paradoxical deconditioning, as a drop in performance appears to be associated with a combination of hormonal and biochemical deconditioning processes rather than overtraining. Furthermore, exercise does not mitigate those processes, but may, in fact, stimulate them. This would suggest exercise may cause symptoms to deteriorate rather than improve, as reported by many people living with long Covid. Understanding the difference between fatigues related to deconditioning and post-exertional malaise is crucial for any health professional giving advice to patients.

Prognosis

We do not yet know the natural history of long Covid, why people improve at different rates or whether everyone will eventually recover to their pre-Covid-19 health status. The experiences and presentations of long Covid are complex and there are competing views about what causes them and how to treat them. It is, therefore, unwise at this stage to make universal statements about long Covid and how to treat it. While some have suggested a psychiatric cause (Garner, 2019), due to anxiety and the extensive media reporting of long Covid, empirical evidence of physical causes has increased over the last two years, as is discussed in the next section.

Underlying causes

There are some plausible theories for the underlying cause of long Covid. Several imaging studies have shown cardiac, lung and brain pathology associated with a Covid-19 infection; for example, the UK Biobank, having scanned more than 40,000 people before the start of the pandemic, invited hundreds back for a second imaging visit (Douaad et al, 2022). Using matched controls, they found significant, enduring effects of Covid-19 in the brain.

Several small studies of pathophysiology have suggested plausible mechanisms not related to heart and lung function. Singh et al (2022) found a marked reduction in the volume of oxygen uptake at maximum exertion (peak VO₂) along with exaggerated hyperventilation during exercise in some people who have had Covid-19 but do not have cardiopulmonary disease. The reduction in peak VO₂ was associated with only a small difference in oxygen between arterial and venous blood compared with controls, indicating a low level of oxygen diffusion in the capillaries.

It is well established that endothelial dysfunction is associated with poor prognosis in the acute phase of Covid-19 and it may be implicated in long Covid as well (Hartsell et al, 2022). A Swiss study measured endothelial quality by finger thermal monitoring and found fatigue, chest pain and neurocognitive difficulties were markedly associated with poor endothelium function (Charfeddine, et al 2021). Anti-thrombotic drugs may reduce symptoms of long Covid (Wang et al, 2022). Similarly, patient advocates have shown much interest in the work of a South African team reporting amyloid deposits in the plasma of a small sample of people with long Covid (Pretorius et al, 2021). The team hypothesised that these ‘micro clots’ can block small capillaries and thereby inhibit oxygen exchange.

Progress has been made on pharmacological treatments for long Covid. Many symptoms appear similar to mast cell activation syndrome and there are multiple reports that antihistamines are effective
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(Grime et al, 2022). Anticoagulants and statins are used in some long Covid services and Heal Covid (heal-covid.net), a Cambridge-based trial, is exploring whether prophylactic use of these drugs might prevent long Covid in people discharged from hospital after a Covid-19 infection. Patients with acute and long Covid have been shown to experience mitochondrial dysfunction (Hartt et al, 2022); an Oxford trial is looking at whether a drug shown to improve this in patients with liver disease might be effective in long Covid (University of Oxford, 2021).

“We do not yet know the natural history of long Covid, why people improve at different rates or whether everyone will eventually recover to their pre-Covid-19 health status”

The nurse’s role

A recent paper with data from nearly half a million people diagnosed with Covid-19 across 1,392 general practices in England found that, relative to Covid-negative and influenza cohorts, those who had experienced a Covid-19 infection had markedly higher GP consultation rates for multiple new symptoms (Whittaker et al, 2021). Nurses, therefore, have a role in supporting people with long Covid in the community as well as in specialist clinics.

Rather than recovery from an acute infection, long Covid is better seen as a mid-to-long-term condition. Nurses play a pivotal role in supporting people with other long-term conditions in the absence of potential treatments. This can include:

- Managing uncertainty;
- Coproducing personal coping strategies;
- Pacing;
- Health promotion;
- Vigilance for ‘red flags’ of other diagnoses triggered by the acute infection;
- Symptom management;
- Direct support with activities of daily living and psychological support in adjusting to a changed health status.

Whatever the cause, people with persistent symptoms need help and support. Alongside the rehabilitation interventions of allied health professionals, nurse specialists and nurse consultants often have experience in managing similar symptoms in many other long-term conditions. This may include the expertise of pain nurse specialists and stroke and multiple sclerosis nurse consultants in helping recovery or compensation from cognitive dysfunction (brain fog).

Many existing long-term conditions share common symptoms of long Covid (for example, myalgia, autonomic syncope, cognitive dysfunction, post exertional malaise, anxiety and depression). Two of the most common new diagnoses, hypertension and diabetes (reported in the US, Table 1) are well served by clinical nurse specialists, while community mental health nurses have extensive experience in managing anxiety.

Conclusion

Diagnosing the cause of long Covid can be difficult, and there may be multiple simultaneous causal mechanisms. Nurses must keep an open mind, listen vigilantly to their patients, and make early referrals to specialist centres. Nursing already has all the expert knowledge to support people living with long Covid, albeit fragmented across different roles.

The next article in this series will cover the importance of integrating mental and physical care in caring and supporting people living with long Covid and the role of mental health nurses in supporting people with their physical symptoms, while the final article will explore the challenge for nurses living with long Covid, including returning to work safely.


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