

COVID-19 stands alone as one of the few world events to which every country and every citizen has been exposed. Now, with a rapidly growing research body, the disease trajectory has revealed several variations and subsequent long-term health conditions, forcing medical teams to review existing management and treatment strategies to reduce long-term ramifications.

Long COVID (LC) has been identified as a long-term effect of the pandemic bringing new challenges for healthcare teams but the ongoing focus on COVID-19 means LC is given less attention, as are the related consequences and impact on services. LC research and healthcare teams have come together to share their clinical knowledge and experiences, to support each other to best manage patient needs. However, as LC services are rare, the spread of information is limited by geography and access to such networks. The absence of this information is arguably having the greatest impact on primary care services — as the initial source of patient diagnosis and referral to specialist services, this information is vital to patient care.

This article aims to offer a biopsychosocial view of LC considering the context of wider government guidance to further support primary care services in their understanding of LC patient experiences and facilitate their management. While the focus of this article is LC, the impact of COVID-19, the pandemic, lockdown, and related psychosocial impact are also acknowledged as contributing to LC patient experiences.

#### WHAT WE KNOW

**Diagnosis and prevalence.** The LC diagnosis emerged from experiences of COVID-19 patients whose symptoms extended beyond the clinical/governmental understanding of the trajectory. The introduction of a projected time frame for recovery allowed for a distinction between simple COVID and LC symptoms, offering clinicians a platform to inform them of a 'new' disease. Despite this, the diagnosis of LC comes with no agreed upon definition. Indeed, a review by the Centre for Dissemination and Engagement maintains that the current LC profile suggests four different syndromes, each with different causes and treatment plans. According to a report in *The Lancet* (2021), an estimated 945 000 people (that is, 1.5% of the population) in the UK have

self-reported LC, including 34 000 children aged 2–16 years. Prevalence rates appear to be influenced by numerous factors, such as age and sex, with people aged 35–69 and females most affected, as well as factors such as low socioeconomic status, pre-existing health issues, and occupation (particularly healthcare workers) resulting in increased vulnerability/exposure.

**Symptoms.** Greenhalgh *et al* (2020) described LC as a multi-level disease encompassing physical, neurological, and psychological problems (either directly related to neurological issues or as a reaction to impact on quality of life).

**Physical symptoms.** Beaud *et al* (2020) identified early on that cognitive issues ranged from the mild end of the spectrum where LC patients experience a 'blunting of their previous cognitive ability,' struggling with words being on the tip of their tongue, difficulty concentrating, becoming easily distracted, uncharacteristic forgetfulness, memory loss, and general reduced mental stamina, also known as 'brain fog'. Aiyegbusi *et al* (2010), in reviewing prevalence data, identified the 10 most reported symptoms as fatigue, shortness of breath, muscle pain, joint pain, headache, cough, chest pain, altered smell, altered taste, and diarrhoea. Callard and Perego (2021) further expanded on LC symptoms to include skin rashes, palpitations, pins and needles, and mobility issues, with some cases of patients suffering resultant permanent heart or lung damage, irrespective of pre-existing comorbidities.

**Psychological symptoms and influential factors.** Thompson *et al* (2021), in reviewing UK electronic health records, suggest that there are in-hospital factors affecting COVID-19 inpatients that they believe to be predisposing factors, resulting in increased patient susceptibility to mental health problems. These were identified as: pre-existing/comorbid mental health issues, alexithymia, inadequate hospital supplies, and inadequate information. Although focusing on COVID-19, the same issues apply to LC patients, although the context may be in isolation to healthcare services (reducing immediacy of mitigation effects). Mental health problems may arise because of emotional reactions to and interpretations

of the situation and resultant trauma (as distinct from but not excluding PTSD). Specific mental health problems related to LC include PTSD, major depressive disorder, anxiety disorders, sleep disorders, phobias, fears with avoidant behaviours, health anxieties, OCD and adjustment disorder related to living with LC symptoms, social exclusion and addictions (as a form of coping), and neuropsychiatric disorders.

**Gaps in our understanding.** The above lists are by no means definitive, and as our understanding of LC increases, additional symptoms may emerge over time. Practically, this means that making an accurate diagnosis is complex, and at the coal face primary care services have little information or resources to support care for this group. A poignant editorial in *The Lancet* (2020) recommended that part of supporting LC patients was in fact to support primary care, stating that due to the above-mentioned processes, patients were at risk of their symptoms being diminished or ignored, resulting in poor outcomes for patients and services alike.

**Additional influential processes and symptoms.** In attempting to obtain a more complete picture of LC it is important to consider external, influential processes on the diagnosis, treatment, and patient experience of LC. Health policies regarding LC have come from patient experiences informing clinicians and treatment, further informing research, in turn informing government policy. As such we have learnt to focus our attention on patient experiences (many of whom are healthcare professionals), thus allowing for a greater insight into related treatment. We see then that the two groups — patients and health/government bodies — are intertwined, and yet this process is not considered when we reflect on LC patient presentation, which are the basis for forwarding our knowledge. In exploring this link, we may be able to improve our clinical management of LC patients.

**Considering the national context.** Throughout the pandemic both the public and the government have worked with the unknown. Initial management was necessarily reviewed on a daily basis with significant shifts of guidance within

days or sometimes even hours — as new information was identified. Directives were stopped, re-started, changed direction, or were aborted with little preparation and no room for wider public opinion.

This, coupled with a disturbing rapidity of increasing fatalities, resulted in an atmosphere of fear and so (arguably), a readiness to adhere to guidance regarding safety/health behaviours. With an absence of consistent information, the population look to be advised, to be guided and directed; to act or not. Furthermore, they too required *evidence* as to outcomes and effectiveness as eagerly as health bodies did to ensure protection of themselves and their families.

Relatedly, LC healthcare teams were set up in a context of increasing patient numbers and were hard pushed to present immediate and effective outcomes/measures, so that, as with COVID-19, the results could inform the development of further treatment. The pressure to perform has been high, with healthcare professionals feeling that the completion and submission of outcomes and key performance indicators (KPIs) was equal to care. As such, teams have treated quantities of patients with no time to consider more subtle patterns of patient presentation.

*The role of biopsychosocial factors.* We see the impact of physical, psychological, and wider influencing systems at the coal face, on LC patient presentation and their interpretation of expected treatment. Initial primary care consultations may not always allow for the manifestation of these issues and can often result in patients not attending appointments despite urgency of request, being unable to fully retain information, experience problems processing information given, and subsequently affecting commitment/adherence to treatment and engagement with services. The result of these issues on patient experience of care and longer-term clinical management is self-evident. As such, recognition of LC-related patterns of patient presentation may be helpful in identifying those patients warranting further LC investigations.

*Common patient presentations.* The following are a number of patient presentations that colleagues working in LC rehabilitation services have noted. Where physical symptoms may overlap with other health concerns it is perhaps a focus on the nuances of patient presentations and their influences that may facilitate LC management. As a result of bio-

psychological issues, LC patients may regularly:

- Miss calls and appointments, confuse timings, may be seen as lacking in motivation, and not be followed up due to poor attendance and engagement. These memory problems may be perceived as stress-related forgetfulness.
- Be confused regarding information given, have poor recall, and an inability to express themselves clearly resulting in repeated information requests/calls to services, interpreted as poor engagement.
- Alternate between varying levels of motivation regarding treatment that are not consistent with engagement and treatment adherence due to extreme fatigue.

As a result of social/policy issues, LC patients may regularly present as:

- Being helpless, seemingly passive, and lacking in taking responsibility for their health, for example, always relying on/referring all issues to health professionals. Given the guidance has been top-down but the information informing the guidance has been bottom-up, patients are left feeling unsure of their own needs and who 'leads'. As such they may wait for professionals to act without input from themselves.
- Expressing any symptom as urgent due to the daily fatality reporting and direct government-to-public updates on decision-making regarding LC/COVID-19 issues.
- Pressurising professionals to act, feeling that they are having to fight for available treatment due to the publicised warnings of limited healthcare resources, resulting in tense exchanges.
- Lacking faith and expressing negativity towards healthcare professionals, again due to the publicising of reduced input and activity in other health specialties, as has been the case with cancer or other long-term conditions.

The integration and assimilation in the mind of patients between both the handling of COVID-19 and LC have created a very challenging clinical environment, and contribute to an environment of emotional distress and seemingly paradoxical behaviour. This may result in dismissing influences on the patient and their presentation. This coupled

with the pressure on healthcare workers themselves suggests some validity to the earlier-mentioned concern of patients with LC being at risk of their symptoms being missed. As such, strategies need to be put into place to mitigate their impact. These may include simple adaptations to existing clinical practice, such as:

- Offering patients more written and less verbal information during the consultation, allowing them to have information to hand and reduce information overload for those with neurological issues.
- Considering a somewhat extended consultation period in order to express needs.
- Consultations may need to include video consultations (but *not* telephone calls only, which themselves feed into the experiences of social isolation) to support patients struggling with the effects of fatigue or health issues that may make attendance at surgeries a challenge.
- Encouraging patients to take more responsibility for their treatment and identify barriers to motivation in the context of LC symptoms.

*Conclusion.* LC is emerging as a significant consequence of COVID-19. While services are now starting to address the management of LC, there is a lack of information and understanding about patient experience. This may result in LC symptoms being misinterpreted or missed. With the focus on primary care services as the focal point of initial patient consultation and treatment planning, recognition of these issues is important. Simple adaptations to clinical management of LC patients may facilitate the process.

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