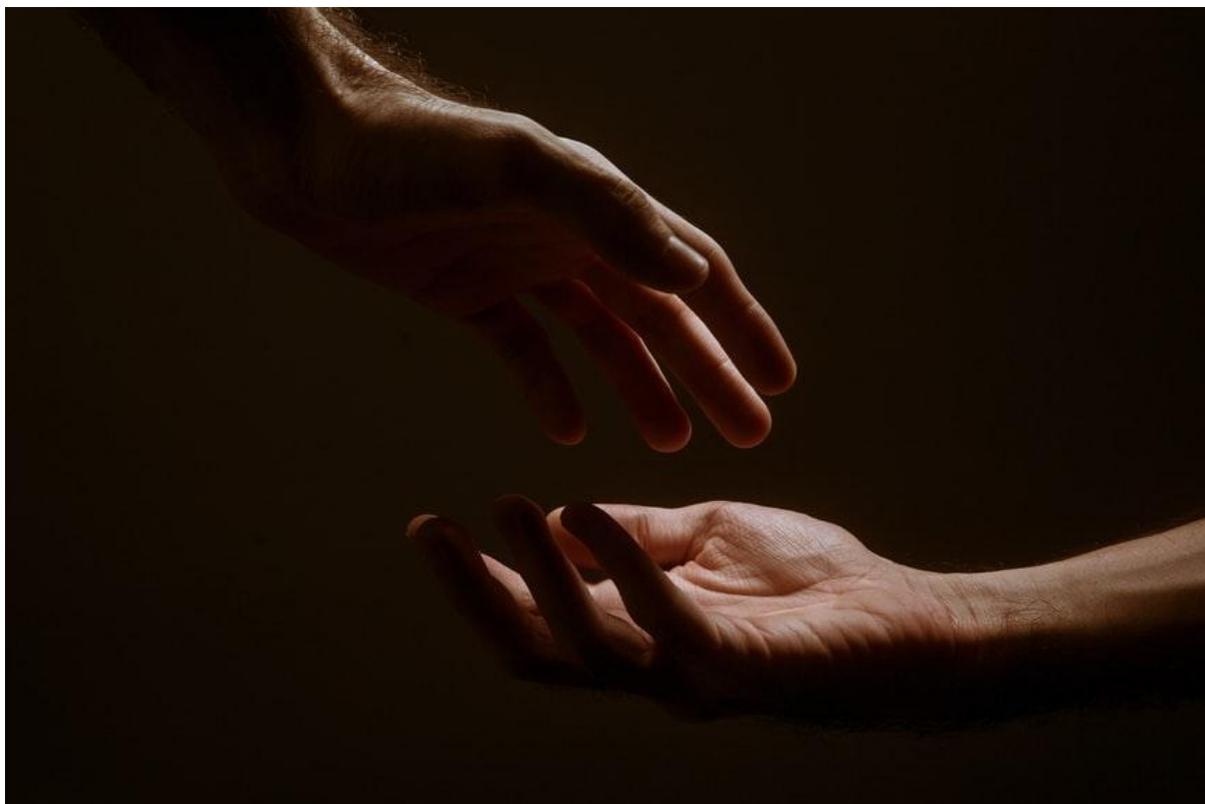




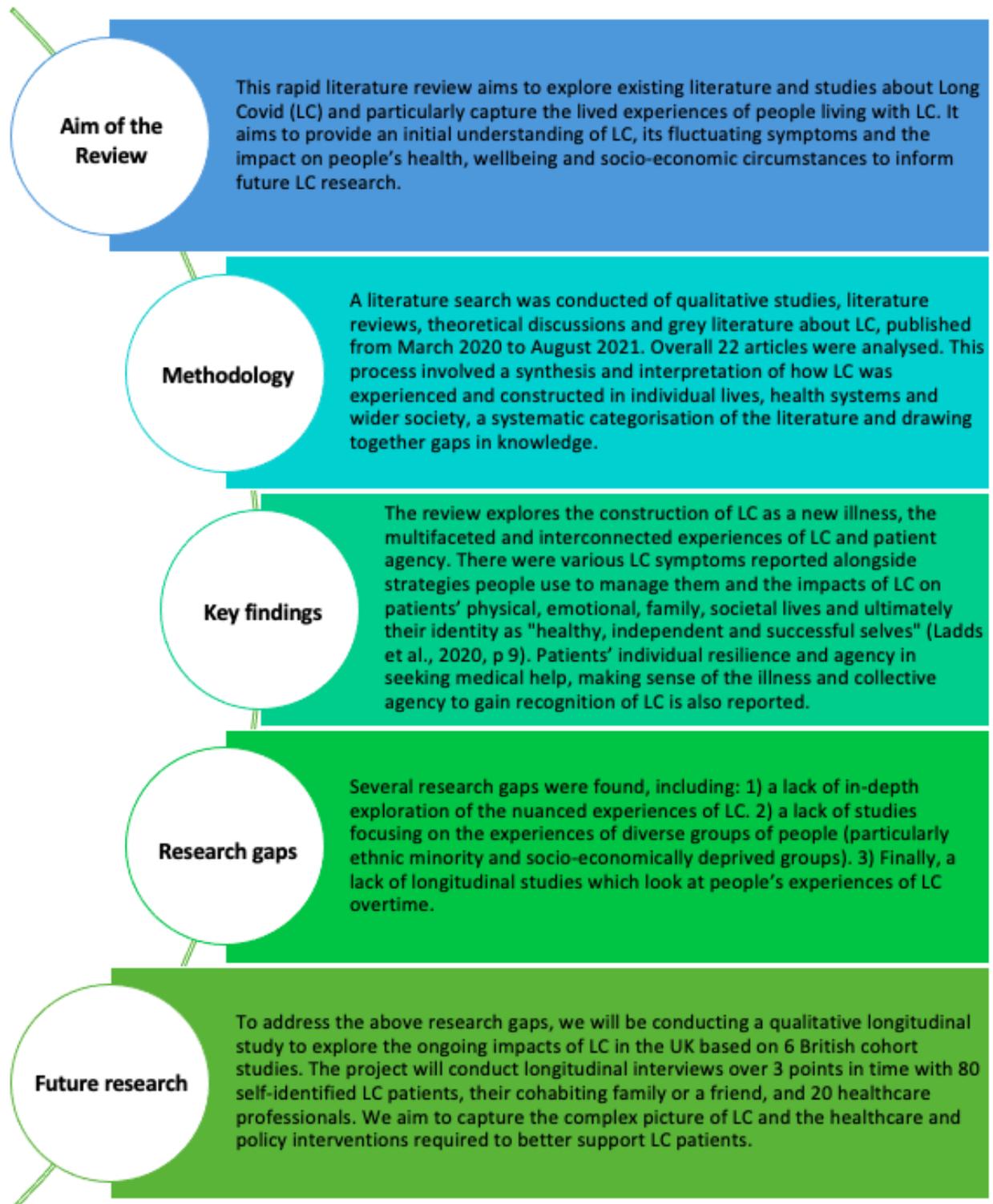
Understanding the lived experience of Long Covid: A rapid literature review



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December 2021

Review summary



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Citing this report: Baz, S., Chao, F., Carpentieri, J.D., and Sheard, L. (2021) Understanding the lived experiences of Long Covid: A rapid literature review. London: University College London.

Acknowledgements

This publication is part of the Coronavirus post-acute long-term effects: constructing an evidence base (Convalescence Study) research project. This research team is working on the Qualitative component of the work package (Qualitative Longitudinal Study).

This work was supported by the National Core Studies, an initiative funded by UKRI, NIHR and the Health and Safety Executive. The COVID-19 Longitudinal Health and Wellbeing National Core Study was funded by the Medical Research Council (MC_PC_20030, MC_PC_20059). Characterisation, determinants, mechanisms and consequences of the long-term effects of COVID-19: providing the evidence base for health care services (CONVALESCENCE) was funded by NIHR (COV-LT-0009).

We would like to acknowledge and thank the six British cohort studies we are working with: Born in Bradford (the parents of children born 2007-2011), the Millennium Cohort Study (born 2000-02), Next Steps (born 1989-90), the 1970 British Cohort Study (born 1970), National Child Development Study (born 1958) and the National Survey of Health and Development (born 1946).

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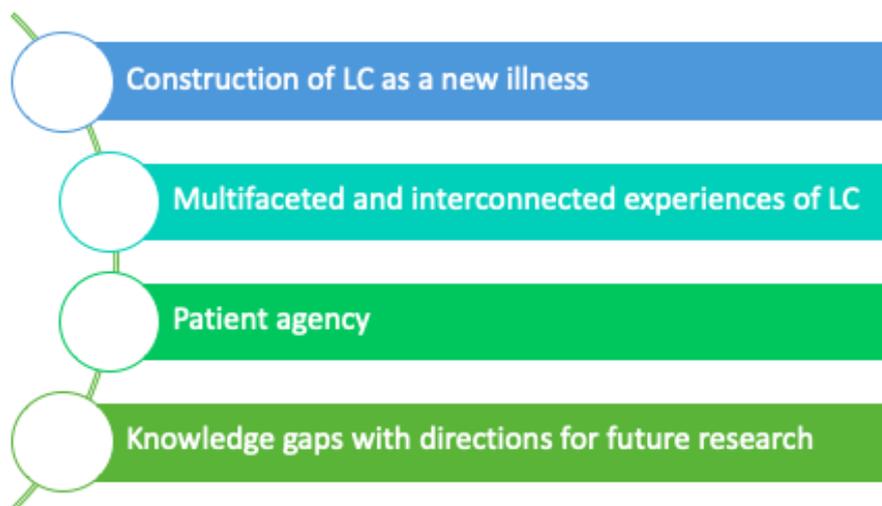
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1. Introduction

Long Covid (LC) has rapidly emerged as both a medical and social issue since 2020, drawing headlines in the public and global domain. In the UK, people experiencing ongoing symptoms of Covid after the initial infection came together online to try to make sense and gain recognition of their condition. Academic research into LC is constantly evolving and seeks to understand the illness from the perspective of those suffering from it. This rapid literature review explores existing studies into LC and particularly captures the narratives of people who have adapted to live with LC. The literature reviewed in this paper largely focuses on providing an initial understanding of LC, how the illness emerged, and the fluctuating symptoms managed by those with LC. Although this literature is predominantly descriptive and has a lack of focus on the ongoing trajectories and experiences of LC, narratives of making sense of, managing, and living with the illness over time are brought to the fore. Such narratives will be presented here by capturing the experiences and stories of those living with LC.

A rapid literature review was conducted analysing academic and grey literature on LC with a predominant focus on qualitative studies identified between March 2020 and August 2021. This paper will begin by outlining the methodological approach to the review and then across four sections will present the following:



The impact of LC on people's everyday lives, health, socio-economic circumstances and identity is also explored. The paper finishes with introducing a new qualitative longitudinal study exploring experiences of people with LC and the interventions required to provide further support in recovery.

2. Methodology

There is a growing number of articles focusing on LC as a new illness, however, the research on LC's impact, especially its socio-psychological implications, remains largely limited. As

such, we conducted a rapid review of academic literature to provide timely evidence-based information to inform future LC research. By following the guidance of the WHO 2017 rapid review framework (Tricco et al., 2017), we used the academic search parameters, including Web of Science, PubMed, Google Scholar and MedRxiv, to identify both empirical and theoretical articles on the lived experiences of LC. Key words used in the search include 'Long Covid', 'long hauler', 'long-term effects of Covid-19', 'post Covid acute syndromes' and 'qualitative'. To capture the immediate and in-depth picture of the lived experiences of LC, we followed the inclusion criteria below to select articles for this review:

- Qualitative studies of adults with LC, and/or literature reviews, and/or theoretical discussions on the impacts and implications of LC.
- Published between March 2020 (when WHO declared the Covid-19 pandemic) and August 2021 (when this review was conducted).

In total 22 eligible academic articles were identified, including eight qualitative research articles, four reviews, and ten discussion papers. In addition to the academic articles, we also consulted grey literature (e.g., mass media) to provide a more comprehensive background of research on LC.

A critical approach was adopted in this review to analyse the selected articles. The review process was threefold, aiming to capture the existing understanding of the lived experience of LC in not only a descriptive but also an analytical manner. First, we conducted careful interpretation and synthesis of how LC is experienced and constructed in individual lives, health systems and wider society. Second, we categorised the findings to systemically elucidate the dynamic and multifaceted nature of LC experiences. Third, we reflexively summarised research gaps and useful theoretical framings in existing literature. Ultimately, we did not intend to conduct an exhaustive literature review on LC but to provide a critical form of knowledge synthesis to inform future research.

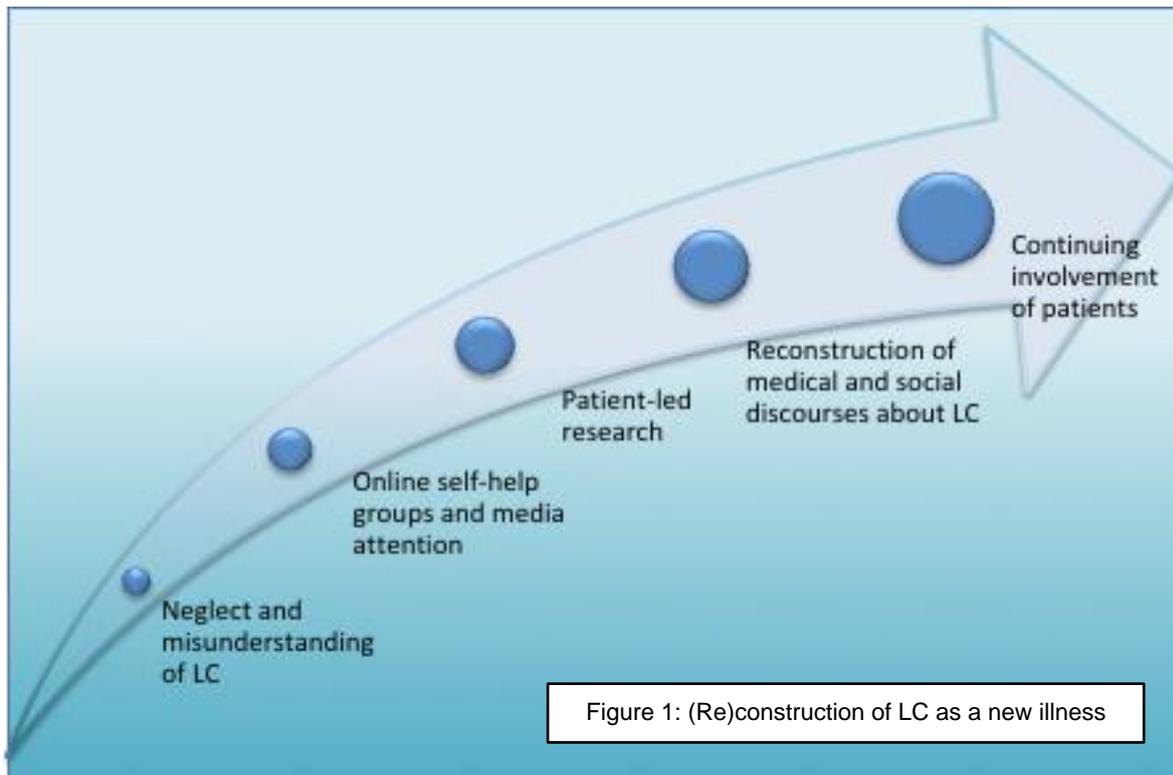
3. Construction of Long Covid as a new illness

LC is said to be the first illness collectively constructed by patients (Callard and Perego, 2021). Clinical evidence from the initial months of the pandemic suggested that most Covid patients experience 'mild' or 'moderate' symptoms and would recover within a short period of time (e.g., 2-3 weeks) (Perego and Callard, 2021). There have been, however, mounting accounts reported by patients that Covid-19 related symptoms (e.g., fatigue, respiratory difficulties, body ache and cognitive dysfunctions) may remain weeks and even months after contracting Covid. Often being neglected and disbelieved in the early stage of the Covid-19 outbreaks,

many frustrated patients shared their experiences in online communities, such as Twitter (#LongCovid and equivalent translations in other non-English speaking countries) and Facebook groups. These narratives vividly depicted patients' struggles with the complex and often fluctuating ongoing symptoms they were experiencing and the indifference (and sometimes even discrimination) they confronted from health professionals, family and friends (Rushforth, et al., 2021).

These online platforms allowed patients to find empathetic audiences and resonant narratives, further fostering a sense of belonging (Perego and Callard, 2021). As such, varied self-help groups formed spontaneously online to actively call for urgent investigations into and appropriate care for their ongoing Covid symptoms (e.g., [Body Politic COVID-19 Support Group](#)). Some groups also commissioned their own research to use patient knowledge to make better sense of their experiences and to further highlight gaps in research and practice. For example, the Patient-led Research Collaborative published a report based on an international survey of LC patients from the US, UK and many other countries in Europe, Asia and Africa (Assaf et al., 2020).

Illness narratives from patients have further contributed to encompassing the developments of social and medical discourses about LC. In light of the widespread patient narratives on social media, conventional mass media also joined the debate to further circulate the daunting experiences of LC. Notably, Ed Yong (2021), who was awarded the Pulitzer Prize for his explanatory journalism on 'long haulers' (a term widely used in the US), wrote varied articles on LC patients' reported struggles, reaching an audience of millions across the globe. Callard and Perego (2021) provided a chronological picture of how patients' narratives about LC became increasingly prominent in British media, including the BBC, and how this media coverage ignited political debates within the UK parliament (p. 2-3). The fast-growing public attention on LC also shaped formal scientific understandings about LC, with an increasing number of prominent scientists/ academics and the WHO beginning to recognise the existence and prevalence of lasting symptoms and sequelae among Covid patients (Callard and Perego, 2021). As such, patient knowledge has been at the heart of the epistemic contribution to understandings of LC: patients have actively exercised their agency to negotiate with varied resources and channels (e.g., media, self-help group, advocacy) to transform LC from an initially neglected condition to a physically and emotionally laden experience that has both scientific and social significance (Rushforth et al., 2021).

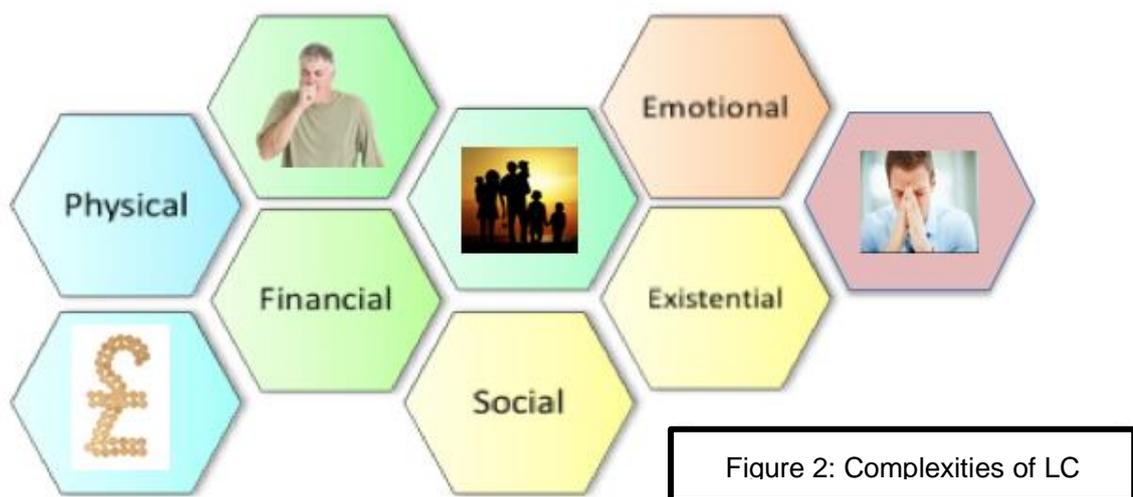


Despite the growing knowledge about LC, definitions of it remain largely vague and fast-evolving. The unstable nature of the definitions is seemingly attributed to the multisystemic and often fluctuating symptomologies of LC and its multidimensional impacts on patients (Aiyegbusi et al., 2021; Callard and Perego, 2021). The uncertainties also lie in the length of LC. Extant academic literature and guidelines have not agreed on how long a patient has to experience Covid related symptoms before being diagnosed as LC – working criteria vary between 4 to 12 weeks (see Ladds et al., 2021; Aiyegbusi et al., 2021; Michelen et al., 2020; Gorna et al., 2021). Given many LC patients’ symptoms are still ongoing, from a longitudinal perspective it is also unclear how long these experiences can last and how these will impact patients’ lives over time (Alwan, 2021). In addition to the above pathological complexities, socio-cultural differences (including different health systems) and inequalities may further contribute to the diverse and even competing criteria for defining LC (Alwan, 2021). As research continues, further clarity can hopefully be added to the evolving definitions and parameters of LC.

LC as a ‘patient-made illness’ also entails an ethical dimension. Given the instrumental role that patients and self-help groups have played in the social and medical construction of LC, ethical challenges remain regarding how to continuously acknowledge and incorporate patient knowledge alongside their illness trajectories. Researchers have argued for the formal discourses (e.g., scientific knowledge, health systems, mental and social support) to more proactively listen to patients and to acknowledge patients’ contributions (Perego and Callard, 2021; Dhairyawan, 2021; Alwan, 2021). However, ongoing debates on the definition of LC remain between patients and medical communities – patients have been continuously

challenged by the professionally defined notion of 'post Covid (acute) symptoms' (Yong, 2021). Patients have criticised this notion, suggesting it is too fragmented and thus fails to capture the chronic and multifaceted nature of their lived experiences (Alyebushi et al., 2021). From a more international perspective, the current understandings about LC are largely based on the western contexts and white populations. Therefore, a more representative approach is needed that better reflects the diverse, multi-cultural and ethnically varied nature of contemporary societies, in the ongoing constructions of LC across the world as well as within each country (Alwan, 2021).

4. The multifaceted and interconnected experiences of LC



4.1 Physical complications

According to Ladds et al (2020, p. 2) people experiencing Long Covid have a "confusing array of persistent and fluctuating symptoms including cough, breathlessness, fever, sore throat, chest pain, palpitations, cognitive deficits, myalgia, neurological symptoms, skin rashes, and diarrhoea". Breathlessness and fatigue are two dominating symptoms. There has been a lack of attention paid to people who have not been hospitalised initially after getting Covid who now have "evidence of cardiac, respiratory, or neurological end-organ damage" and those who have persistent symptoms with no organ damage (Ladds et al., 2020, p. 2). There is now some emerging literature of how these multisystemic and fluctuating physical complications severely impact people's everyday lives, health and wellbeing, how people seek to manage the illness and attain support from health services, family, and friends.

Managing symptoms and making sense of the illness

People living with LC have described managing symptoms and making sense of the illness – often being forced to do so on their own. Kingstone et al (2020, p. 5) discuss the "hard and heavy work" of patients in enduring and managing symptoms, gaining access to health care and experiences of living in uncertainty and fear. Participants described having to manage symptoms alone without seeking the help or support of a GP (Kingstone et al., 2020). Those living with LC had to set realistic goals and pace themselves, for example giving themselves a break when doing household chores (Kingstone et al., 2020; Maxwell, 2020). They also sought a range of support including, peer support, online support, complementary therapies, special diets, and supplements (Kingstone et al 2020). Patients stressed the importance of resting (Humphreys et al., 2021). Callan et al. (2021) conducted a longitudinal study focusing on LC and brain fog. They conducted interviews and focus groups with follow up emails after 4-6 months of the initial interview (12 months into having LC), and described participants adopting coping strategies such as lowering self-expectations and prioritising rest. These strategies involved complex self-negotiation and activity trade-offs such as a limited return to work.

Maxwell (2020) has found that those living with LC can also suffer from poor mental health including low mood, depression, and anxiety. There was a particular sense of anxiety for those who were left in a "no man's land" about the severity of their Covid condition. Inconsistent advice from health professionals led to people carrying on as normal despite not having fully recovered, and there was a lack of information about the fluctuating nature of symptoms (Maxwell, 2020). After recovering from one symptom, it was devastating to find another appearing. A mismatch between advice and actual experiences created anxiety about why patients were not recovering. There were a wide range of Covid symptoms making people severely debilitated with different patterns emerging, for example for some a cough came later rather than at the beginning of the infection and others experienced fainting as a first sign of infection (Maxwell, 2020). Severe symptoms like high blood pressure and unbearable heart pain occurred some weeks into the illness. Managing this change in physical symptoms over time and the associated unpredictability was stressful, causing anxiety (Maxwell, 2020).

Physical activity

Humphreys et al's (2021) comprehensive study explored LC and the role of physical activity (PA). Four key themes were identified: the interconnection of physical and psychological symptoms; lack of clear and consistent PA-related advice; learning to balance symptoms and activity; and adapting to an altered life. All participants reported PA as being drastically reduced. Participants were housebound for many weeks or months. Self-care and housework became difficult; formal exercise was 'inconceivable' (Humphreys et al., 2021). Medical professionals did not give conclusive advice on how to manage PA. Thus, participants turned to online sources looking for information on other viruses. It was difficult to engage with PA as this would lead to fatigue, relapses, breathlessness and heart palpitations. Many patients

described using their limited energy reserves strategically, planning their day and selecting activities that would benefit their wellbeing such as walking, getting outdoors, or fulfilling caring duties (Humphreys et al., 2021).

Guidance of PA was not tailored to the complexity of LC. Humphreys et al's (2021) research suggests that pacing should be tailored to the individual, based on biographical factors, the life-stage, current physical function and activity history, and that patients should be monitored (by professionals or via self-monitoring). Patients who saw PA as being core to their identity pushed themselves to do PA even if this caused relapses, whereas others feared the impact PA would have on their long-term health. The authors also argue for a multidisciplinary approach to support people with PA, collaborating with sports medicine, centres of well-being, behavioural science and a range of medical professionals (Humphreys et al., 2021). Humphreys et al. (2021) found that family and friends were also very important in supporting participants and became 'physical activity companions', for instance accompanying participants on everyday walks. Activities of daily living (ADLs) such as housework, gardening and outdoor activity were very important for normality and mental health.

In other research (Kingstone et al., 2020), patients have reported that the NHS 'Your COVID recovery' website's recommendation of graded activity was 'unhelpful', leading to negative impacts for some. One participant said that she could not get out of bed after following the recommendation. Demonstrating the potentially confusing messages and recommendations from healthcare services while they seek to understand LC, one participant in Humphrey et al's (2021) study described a doctor recommending that they not push themselves too much physically. Dé Cary et al. (2021) promote a "Stop. Rest. Pace" principle to help manage LC patients' lives and recovery in a safe manner. A key message from this editorial is the importance of not over-burdening LC patients with their proposed rehabilitation and other exercises, as mismanagement of physical activities may cause harm instead of improving LC patients' conditions.

The findings from these studies illustrate that LC has an impact on people's day-to-day life and functioning, making it difficult for individuals to fulfil their normal everyday responsibilities. Pacing and prioritising are presented as useful strategies to manage LC (Kingstone et al., 2021).

4.2 Emotional distress: stigma, disbelief and loneliness

Existing studies illustrate a sense of stigma, guilt, shame, and feelings of loneliness amongst LC patients (Ladds et al., 2020; Callan et al., 2021). For example, Ladds et al's (2020) study highlights a heavy sense of loss and stigma amongst those living with Long Covid.

In a NIHR report about 'living with Covid' (Maxwell, 2020), there was a sense of stigma amongst participants about not being believed about their illness by health professionals, employers, or family and friends. Particularly as LC was a new and emerging phenomenon, this lack of trust made people feel very isolated and lonely, and led to them questioning themselves and their condition. Iqbal et al. (2021) have argued for the importance of educating patients and the public about the nature of LC to reduce the stigma associated with it.

Callan et al. (2021) have found a sense of guilt and shame in relation to difficulties returning to work or previous levels of function; these sensations are exacerbated by the lack of understanding from others about these problems. Participants stated that they had to conceal difficulties they were facing that were not physically visible to others, such as difficulties with language and memory (Callan et al., 2021). Participants found themselves in a frustrating, stigmatising, and frightening situation, with LC damaging their functional ability, personal and professional identity.

In exploring the experiences of doctors with LC, Taylor et al. (2020) have found that this group felt a sense of guilt and stigma about being ill. This is associated with a culture of invulnerability within medicine: doctors felt that being ill could be seen as a weakness or letting down the profession. However, the experience of having LC, and of facing difficulties themselves in finding medical help within the NHS, helped doctors to understand LC experiences from the perspective of patients themselves. These doctors thus felt that they would be able to offer more support and empathy to LC patients in their own practice (Taylor et al., 2020).

4.3 Lack of support from the health care system

Existing studies find that people with LC often experienced a lack of support or clear advice from health professionals, NHS services and GPs (Ladds et al., 2020; Maxwell, 2020; Callan et al., 2021; Humphreys et al., 2021). LC patients felt that they required more guidance from health professionals (Humphreys et al., 2021). Participants in Kingstone et al's (2020) study found it hard to find a GP who would believe their symptoms were real, although they acknowledged the uncertainty faced by doctors at the time due to a lack of knowledge and evidence of LC as a new emergent illness.

Patients had to work hard to demonstrate that their symptoms were real and attempted to persuade healthcare professionals to help them (Kingstone et al., 2020). Neurocognitive symptoms of LC added difficulties to communicating and self-advocating with professionals (Callan et al., 2021). Patients also faced discontinued and often fragmented care (Ladds et al., 2020).

In Callan et al's (2021) study participants felt frustrated, angry, and hopeless when healthcare professionals dismissed their symptoms as "in your head", secondary to depression or anxiety or not being real. On the other hand, where participants' symptoms were acknowledged and they felt believed there was a "sense of huge relief and validation", which they perceived to be a small victory (Callan et al., 2021).

Recommendations for improvements in health services in these studies include patients being assessed face-to-face, investigating the cause of symptoms, taking a multi-disciplinary approach, having a one-stop clinic and receiving continuous support from the GP at every stage of the illness (Kingstone et al., 2020; Taylor et al., 2020; Callan et al., 2021). Atherton et al. (2021) emphasise the importance of 'relationship-based care', arguing that the patient-doctor relationship is vital in the management of people with LC. They argue that GPs need to listen to LC patients and their families, offer empathy and support, and help to navigate the illness and in putting everything together. Professionals need to listen to patients (Ladds et al., 2021). Participants in Kingstone et al's (2020) study also emphasised the importance of the GP helping patients at every stage. Finally, Ladds et al. (2021) recommend the importance of integrating different healthcare services and specialities through a one-stop shop service in primary care run by generalists rather than a single specialist, allowing for continuity of care and personalised rehabilitation. This would involve integration and education of allied healthcare professionals, psychologists and occupational health teams.

4.4 The role of family, friends and partners

The lack of understanding of LC expands beyond the medical sphere to employers, family and friends, which can leave people frustrated (Humphreys et al., 2021). Participants in Kingstone et al's (2021) study cited not being believed by family and friends, particularly due to the invisibility of some symptoms. For example, one patient in this study was told by her GP that she was experiencing anxiety (rather than having breathlessness due to lung damage) and that there was nothing else wrong with her. Her husband was not supportive either, so when she informed him of this diagnosis it made everything worse. A lack of support from her partner led to the participant feeling very lonely with no one to talk to (Kingstone et al., 2021). Other experiences included LC sufferers constantly having to explain why they were resting.

However, the important role of family and friends in providing support to those with LC is also emphasised in studies.

Family played a crucial role in supporting those with LC; this included family being informal carers, supporting self-care activities such as cooking, providing emotional support and over time understanding what LC is (Humphreys et al., 2021). Maxwell (2020) emphasised the importance of support from spouses, family and friends in recovery.

However, the cyclical nature of the illness can be very difficult for supportive family and friends who may celebrate any small improvement in health and then struggle themselves to cope with patient relapses. Thus, as well as support for LC patients, ongoing support for family and friends is also required (Maxwell, 2020).

4.5 The impact on employment

In Callan et al's (2021) study, participants described an inability to return to work at all or to their normal functional level. Those who did return to work reduced hours or asked others to check their work which linked into anxieties about making mistakes, self-doubt about abilities, lack of self-worth and a changed professional and personal identity (Callan et al., 2021). Furthermore, experiencing symptoms such as fatigue and brain fog 'severely limited' prospects of returning to work or finding new employment for those experiencing ongoing symptoms (Ladds et al., 2020). The debilitating symptoms of LC like brain fog, sore throats and severe fatigue impacted not only one participant's health but also her work and social life (Maxwell, 2020). The uncertainty of the condition meant that it was difficult for her to predict when she would fully recover (Maxwell, 2020).

In a *Guardian* article the experience of one single mother is captured (Pidd, 2021). The single mother experiencing LC lost her job and was facing financial struggles living on Universal Credit, having to use savings to pay bills. She experienced tiredness and difficulty in walking. She felt her life, in which she had worked hard to provide security for herself and her child, was slipping away.

A study focusing on doctor's experiences of LC found that doctors were often expected to come quickly back to work; many doctors expressed fears of returning too soon (Taylor et al., 2020). Thus, LC has significantly transformed and impacted people's livelihoods, financial circumstances, ability to lead their normal working lives and return to work.

4.6 Loss of meaning and identity

Overall, LC has been found to impact people's identity and sense of self. Ladds et al. (2020, p 9) found that a "spoiled identity" was common amongst their 114 LC participants; the illness not only impacted activities and routines but also their identity as "healthy, independent and successful selves". Callan et al. (2021) also state that chronic illnesses can create a 'spoiled identity' and disrupt a sense of purpose and self. LC can disrupt an individual's professional self, interpersonal relationships, and overall sense of who one is. It can be hard to resume activities that are central to an individual's core identity, including parenting, PA and employment (Humphreys et al., 2021). Humphreys et al. (2021) found that particularly for young participants LC has an impact on their sense of self. They face a significant psychological struggle and have to adjust to an uncertain future. It is evident from the literature that there are identity related struggles from LC, disrupting everyday life, functioning and futures. Overall, it is also important to focus on the socioeconomic impact of LC, including return to work, impact on finances and identities, alongside the impact on health.

5. Patient agency



Figure 3: Patient agency in facing and dealing with LC

Unique in patients' responses to LC is their active negotiations with society to have their voice heard and needs addressed in various ways. As discussed above, patients have collectively constructed the parameters of LC, often through online communities. Rushforth et al. (2021)

explored 114 UK-based LC patients' 'illness narratives', capturing their lived experiences of LC in the intersections between their individual lives and socio-cultural structures. Despite the individual agency of LC patients being neglected in the early onset of the pandemic, they often sought to reach out to their fellow patients and like-minded professionals to challenge the prevailing discourse of Covid-19 as a short-lived respiratory disease (Callard and Perego, 2021). The collective agency of LC patients can also be seen from the varied patient-led research activities, which have been conducted by patients for their own benefit. Patient groups, such as [the Patient-Led Research Collaborative](#), have comprehensively conveyed vivid pictures of patients coping with LC. Their findings have affirmed the widely recognised LC symptoms (e.g., fatigue, brain fog, respiratory issues) and also highlighted experiences and issues (e.g., social and mental impact, menstrual change) that were initially overlooked by the medical community (Assaf et al., 2020).

The LC patients' agency lies in their endeavours to reshape the 'broken' healthcare systems (Rushforth et al., 2021). LC patients have voiced their frustration, emphasised the importance of finding the 'right' GP (who will demonstrate understanding, empathy and support), and demanded improvements more broadly within the health services (Kingston et al., 2020; Callan et al., 2021). By using storytelling as an accessible medium, LC patients have united their individual narratives of suffering to construct "a shared account of rejection by the health system, and a powerful call for action to fix the broken story" (Rushforth et al., 2021: 7). The patients' contributions to develop a more LC-competent care system has been further compounded by healthcare professionals who have suffered from LC. Being both a patient and a practitioner, they have drawn on their professional knowledge alongside patient experience to more directly and adequately shape the ongoing construction of support and care for LC patients (Taylor et al., 2021).

Another, often overlooked, aspect of patients' agency in facing LC is their individual resilience. While having to cope with the multifaceted challenges and deeper distresses (e.g., loss of identity) of living with LC, patients have shown their resilience to develop varied self-management strategies to legitimate their experiences and navigate their everyday lives (Kingston et al., 2020). For example, some LC patients challenged doctors' advice on graded exercise, which they found was detrimental to rather than beneficial for their recovery (Callan et al., 2021). As social beings, patients have also actively sought understanding and support in the rich matrix of their relationships, often from their family and friends as informal carers (Humphreys et al., 2021). Many patients turned to advocating online and/or participating in research as means of revealing their 'fragmented inner monologue' and reforming social discourses on LC. Despite patients' dynamic responses, their agency remains largely overlooked due to the absence of adequate health and social care, as well as the over-emphasis on the authority of professional expertise (Kingston et al., 2021; Callard and Perego, 2021). Therefore, a more patient-centred approach has been called for to empower LC

patients in the doctor-patient relationship and further improve their access to care and support at a more holistic level (Ladds et al., 2021).

6. Knowledge gaps and directions for research



Given the rapid pace of research on LC, understanding about it as both a medical and socio-psychological experience will undoubtedly continue to evolve in the coming months and years. One significant knowledge gap we have observed in this review is a lack of in-depth analysis of the nuanced experience of LC. A number of short academic articles, including editorials, perspectives and commentaries, have briefly discussed a broad range of the issues that need to be addressed in future LC research and practice (e.g., inequalities, inadequate healthcare resources and guidance, patient agency) (e.g., Gorna et al., 2021; Alwan, 2021; Callard and Perego, 2021). Meanwhile, evidence-based qualitative and quantitative studies have revealed the varied causes, experiences and impacts of LC in patients' physical, emotional, family and societal lives (Humphreys et al., 2021; Kingston et al., 2021; Callan et al., 2021; Petersen et al., 2020). These studies, however, are largely descriptive in nature and thus have not yet developed in-depth understandings of how individual meanings and socio-cultural norms are embedded in the lived experience of LC patients. While it is not inconceivable that academics are still at a relatively early stage in their exploration of LC, as a new and greatly complicated entity, we argue that future research should pay more attention to LC as an embodied experience that interconnects the patient's body, relationships and the very meaning of their social and existential being (e.g., how persistent bodily disorders challenge patients' taken-for-granted identities as a healthy and/or autonomous being).

Another overlooked aspect of LC experiences is the inequalities faced by patients from varied backgrounds. Those in deprived areas and from ethnic minority groups may have particularly high instances of LC and the challenges they face can be compounded by both LC and their disadvantaged socio-economic position (Katikireddi et al., 2021; ONS, 2021). This dimension of LC experiences has been largely underexplored (Alwan, 2021). There is also a lack of research on ethnic minority groups in current LC research, which is predominantly based in the western context and often sees LC patients as a homogenous group. Future research needs to integrate LC patients from diverse social and ethnic backgrounds to better represent the demographics of wider society. By drawing on the rich body of literature regarding inequalities in health and social care (not necessarily on LC), further investigations should explore how deprivation and structural racism can disempower LC patients from accessing adequate care and further challenge their multifaceted well-being. For example, Meer et al (2020) state that there is an increased risk of ill-health amongst ethnic minorities reflecting underlying inequalities in housing, employment and income. Socioeconomic disadvantage and racial discrimination within the healthcare system can lead to misdiagnosis and inequality in access to healthcare services (Qureshi 2019; Meer et al 2020). Inequalities are also present for those facing gendered and age-related discrimination. Medical research has found that women and those in particular age groups and with certain health conditions are at higher risk of suffering from LC complications (Sudre et al., 2021); however, their lived experiences and needs have been largely under-researched thus far. Therefore, it is important and necessary to integrate LC patients' biological and biographical characteristics into future research.

There is also a lack of longitudinal elements in current understandings of LC, despite the condition being experienced in a persistent and often fluctuating manner. Most empirical studies have failed to capture the illness trajectories of LC, how the ongoing experience of LC symptoms continuously shape patients' everyday lives, and how fast-changing medical and social dynamics can shape the lived experience. The few exceptions to this include Callan et al. (2021) who explored the progressing symptoms of brain fog through follow-up interviews. The lack of ongoing perspectives limits our understanding of LC as a more chronic condition that requires longitudinal observations and analyses to continuously identify and support LC patients' values and needs alongside their illness trajectories.

Finally, despite LC being claimed as a completely new illness, it is not an entirely foreign experience in biomedical and social research contexts. Researchers have drawn on other chronic illnesses, such as myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS), to navigate their explorations of and resultant support for LC patients. For instance, based on experiences of mismanagement of ME/CFS patients, Décary et al. (2021) emphasise the importance of managing LC rehabilitation in a safe and person-centred manner. Not only can research on LC symptomology learn from previous research, the social research on LC patients' experiences can also seek inspiration from many existing studies on illness, body and

other relevant topics in wider paradigms. During this review, we confronted two prominent theoretical lenses that we believe are of particular relevance to our LC project: (1) illness narratives which can provide a social constructionist ontology to understand how socio-cultural norms speak through individual experiences of LC (Kleinman, 1988; Rushforth et al., 2021), and (2) testimonial injustice,¹ which highlights an epistemological stance to acknowledge the knowledge and lived experience of LC patients as an overlooked group (Fricker, 2007; Dhairyawan, 2021). It is worth noting that we are not suggesting the above lenses are the only theoretical frames to explore LC, as more theories will be incorporated into understanding LC as ours and others' research progresses.

7. Conclusion: a new study exploring ongoing experiences of Long Covid

This rapid literature review has illuminated key knowledge gaps in understanding of LC as a unique and multifaceted experience, which may be closely connected both to people's physical conditions and their socio-demographic circumstances. To address the above gaps, we have launched a qualitative longitudinal project to explore the ongoing experiences and impacts of LC in the United Kingdom based on six British cohort studies². This project, which is a collaboration between University College London (UCL) and the University of York, will conduct longitudinal interviews with 80 self-identified LC patients, their cohabiting family or a friend, and 20 healthcare professionals. We will oversample LC patients from ethnic minority and disadvantaged socio-economic backgrounds (particularly, South Asian backgrounds in Bradford) to explore how underlying inequalities may further shape the lived experience of people with LC. By adopting an in-depth and open-ended approach to our interviews, we aim to understand both the complex and fluctuating symptoms associated with LC and also how living and coping with LC is shaped by and also shapes individual lives, health systems and wider society. As such, our project will focus on how LC patients, family members and wider support networks perceive, live with and respond to the multifaceted effects of LC. The analytical lens of our project is reinforced by the longitudinal approach – collecting three waves of interviews from a diverse range of participants over 18 months between Autumn 2021 and Spring 2023. As such, this project can help capture complex pictures of Long Covid and its illness trajectories, capturing more clearly the intersections between individual lives and broader socio/health structures. Furthermore, we will investigate how these experiences may shape LC patients' ways of making sense of their health, relationships, social lives and the sense of who they are during and even beyond their illness trajectories. We hope that such vivid and reflexive evidence will contribute to

¹ Testimonial injustice refers to a form of epistemic injustice where a person's voice is discounted and their credibility of knowledge is overlooked due to their socio-cultural identity/status (e.g., gender, ethnicity, class, profession).

² These cohort studies include Born in Bradford (the parents of children born 2007-2011), the Millennium Cohort Study (born 2000-02), Next Steps (born 1989-90), the 1970 British Cohort Study (born 1970), National Child Development Study (born 1958) and the National Survey of Health and Development (born 1946).

improving practice and policy, helping to better recognise and support the needs of LC patients, their family and social networks and wider social-health care structures.

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