Longitudinal Qualitative Study of Understanding Individuals' Experiences of and Perspectives on long COVID

Introduction

The COVID-19 pandemic has created considerable issues for the healthcare system in the UK (Rathnayake, Clarke and Jayasinghe, 2020), and there has also been a prevalence of ongoing symptoms following COVID-19 infection in the UK (Ayoubkhani, 2021). Overall, according to the latest data from the Office for National Statistics (ONS) from March 2023, around 2.9% of the UK population self-reported having Long COVID (LC) symptoms (Ayoubkhani, 2021). At the peak of the pandemic in 2020-21, the ONS estimated that 11.7% the UK population would consider themselves as experiencing long COVID symptoms 12 weeks post-infection (Ayoubkhani, 2021). More specifically, LC symptoms are often multisystemic, which means that these symptoms "could encompass respiratory, cognitive and cardiovascular issues" (Baz *et al.*, 2022, p. 2). Therefore, it could be argued that the management of LC symptoms should also reflect the multisystemic feature of LC symptoms, which means that the support provided with people living with LC should be ongoing, holistic and adaptive to its often-changing nature (Fang *et al.*, 2023). However, there has been an extensive literature showing, especially in the UK context, that the support from healthcare system for people living with LC is often constrained, where the resources available could be limited and difficult to access (Baz *et al.*, 2022, p. 2).

Though there has been an increasing number of literatures aiming at understanding and treating LC as well as scrutinising the healthcare system, there is still limited understanding of individuals' experiences of coping with these symptoms and accessing healthcare system (Baz *et al.*, 2022, p. 2). That is to say, current literature has often viewed healthcare as a broad construct, assuming that people with LC have been negotiated with it, yet very little attention has been given to how individuals encounter healthcare system as well as individual needs (i.e. drawing upon individual narratives) (Baz *et al.*, 2022, p. 2). Therefore, the longitudinal qualitative study of understanding individuals' experiences of and perspectives on long COVID (Long COVID study) has adopted a person-centred approach to understand the challenges of people living with LC when interacting with healthcare system. As a result, person-centred care provides an important lens through which to examine how standardised healthcare systems affect individual needs (Braun and Clarke, 2013).

In this following report, a literature review will be provided to give details about the Long COVID study, explaining what the study is about and why the research has been carried. Then, the methodology section will briefly explain how pen portrait and thematic analysis are used to summarise and analyse the data generated from the Long COVID study. Following that, the findings section will be used to present some of the major themes that were generated from the thematic analysis. Finally, a conclusion will be provided to give a summary of the thematic analysis and offer any potential implications of the research.

Literature Review

Long COVID, also known as post-COVID syndrome, is a term that could be used to describe the persistence of symptoms in those people who have recovered from COVID-19 (i.e. tested negatively in PCR tests) (Raveendran, Jayadevan and Sashidharan, 2021), where the symptoms could be continuous or relapsing and remitting in nature (Nabavi, 2020). Depending upon the duration of symptoms, post COVID or Long COVID can be divided into two stages-post acute COVID where symptoms extend beyond 3 weeks, but less than 12 weeks, and chronic COVID where symptoms extend beyond 12 weeks (Greenhalgh *et al.*, 2020).

The Long COVID study aims to understand individuals' experiences of and perspectives on long COVID and healthcare experiences under the UK context, where in-depth interviews were conducted with 40 geographically dispersed participants with self-identified LC across the five cohort studies hosted at UCL Centre for Longitudinal Studies (CLS, 2024) as well as 40 participants from the Born in Bradford study (Born in Bradford, 2018). The recruitment of participants from nationally and regionally representative cohort studies allows the researchers to recruit participants across age groups (spanning ages 20 to 75 years) and get access to comprehensive health records of the participants, which helps them facilitate a more holistic understanding of experiences and perspectives at different stages of the life course (Baz *et al.*, 2022). Notably, the study also placed a specific focus on a region in northern England characterised by great levels of economic deprivation and higher proportion of ethnic minorities, providing the researchers with opportunities to examine how social and racial inequalities may be disproportionally contributed to people facing healthcare challenges with LC in the UK (Ladds *et al.*, 2021).

The are three waves of qualitative interviews conducted between the autumn of 2021 and winter-early spring of 2022-23, where each wave was around 5 months apart. The

interviews have adopted a person-centred approach where the interviewers focused on the lived experiences of people with LC, including their social relationships, employment, education and experiences of healthcare services. In terms of analysing the data, due to the longitudinal nature of the study, a reflexive thematic analysis approach was employed to interpret the rich data. That is, the data analysis process focused very much on the exploring the changes of individual experiences over time (Neale and Flowerdew, 2003). Namely, the data analysis process goes through three phases: description, analysis and interpretation, which aims to understand "'if/what changes had occurred', 'how/why these changes might have happened' and 'what is the meaning and impact of these changes'" (Baz *et al.*, 2022, p. 5).

Methodology: pen portrait and thematic analysis

Pen portraits are adopted for the purpose of summarising data generated from the Long COVID study. The primary reason for using this method is because the data that longitudinal qualitative research generates has often had a large volume of complex data over a span of years, and pen portraits "provide a useful framework to enable researchers to conduct a robust analysis of multiple sources of qualitative data collected over time" (Sheard and Marsh, 2019, p. 1). The process of generating a pen portrait often includes four key stages (Sheard and Marsh, 2019): 1) understand and define what to focus on 2) design a basic structure 3) populate the content 4) interpretation. The first stage often involves in the research team going through a series of discussions and reflections to de-mystify the major emphasis of the analysis, which prevents the pen portraits from becoming a narrative catch all. The key to the second stage is to design a basic structure relevant to the dataset in question to allow narrative account to become relatively free flowing and open without attempts to stifle or unnecessarily quantify the qualitative data. Thirdly, the content of the pen portrait should be descriptive and discerning in the sense that it should detail the events that are happening between different time points, highlighting the trajectory of a chosen focus. The last stage should be aiming to go beyond the description and develop conceptual notions to explain what is occurring in the data, where these conceptual notions could be categorised into "themes" to allow thematic analysis to be devised to allow further analysis.

Thematic analysis as a flexible approach to analyse qualitative data aims to develop patterns of meaning across a dataset to allow researchers to understand people's experiences and perceptions (Braun and Clarke, 2022). In this particular research project, the analysis is approached from a more inductive way, which means that the

themes are directed by the content of the data rather than existing concepts or ideas (Braun and Clarke, 2022).

Findings

Theme 1: Fatigue as a common LC physical symptom

Fatigue could be referred to as an ongoing physical symptom that participants experienced after the infection of COVID, which not only affects their physical wellbeing negatively but also interrupts other aspects of their life such as mental health and social life. According to the latest report from the ONS, fatigue continued to be one of the most common symptoms reported by individuals that experienced Long COVID, where 72% of those with self-reported LC reflected having fatigue-related issues. Likewise, fatigue is also reflected across the interviews, where typical symptoms normally include low levels of energy and lack of motivation to engage in everyday activities.

One of the major features of fatigue-related issues is that the occurrence of physical fatigue fluctuates across time, or, according to the participants, they come in waves. For example, among the three participants in which thematic analysis was conducted, Catrin highlighted how physical tiredness after her COVID infection “came in waves…so one minute you’re fine and then the next you’re not” and “it’s fluctuating. Some days I’ve got loads, the next I have none.” Similarly, Amy reported severe lethargy after her first COVID infection in her first wave of interview, concluding that "I was so lethargic that I couldn’t really leave the apartment by myself." Despite having gradually recovered from her fatigue issues since her first COVID infection, the symptoms became aggravated when she caught COVID again, where she stated in her second interview that It was just kind of like mentally my head felt heavy…I would sleep for long times and then when I couldn’t sleep I would still be in bed ‘cos my body felt too tired to get up." These insights collectively underscore the non-linear and unpredictable nature of post-COVID fatigue, with participants reporting experiences of sudden and severe energy depletion followed by periods of relative recovery. The variability of fatigue symptoms suggests that recovery may not follow a straightforward or consistent trajectory, complicating both the personal management of these symptoms and the broader understanding of fatigue in the context of post-COVID recovery.

Theme 2: Difficulty in accessing healthcare system

Difficulty in accessing healthcare system in the UK context mainly refers to the participants being unable or finding it difficult to get access to GP service for their LC symptoms, where either GP had very little specialist knowledge in terms of treating LC symptoms, or the NHS system does have the physical capacity to offer healthcare services in time, leaving participants choosing alternative methods such as self-treatment at home or going to private clinics to alleviate their symptoms.

The experiences of the three interviewees reflect a shared struggle with accessing healthcare in the UK, particularly when seeking support for issues related to LC. Despite having distinct experiences in navigating the healthcare system, all participants implicitly highlight the strain on resources within the NHS, which seems insufficient to provide the comprehensive care required for individuals dealing with LC.

Amy, for instance, experienced persistent asthma symptoms following her COVID infection. She faced significant challenges in securing a GP appointment, despite her efforts, recalling how she spent considerable time calling her GP daily without success in obtaining a consultation. This reflects the difficulties many patients face in accessing timely care, particularly for ongoing or chronic conditions like those associated with long COVID. Similarly, Catrin encountered systemic delays when seeking help for her ADHD diagnosis after contracting COVID. While she was "nearly on the NHS," her experience was characterized by long waiting times and procedural inefficiencies, further illustrating the healthcare system’s struggles to meet the growing demands placed on it by individuals with complex post-COVID conditions. These experiences collectively underscore the limitations of the UK's healthcare system in managing the long-term effects of COVID-19. The interviewees' difficulties in accessing appointments and navigating a slow and overwhelmed system point to broader systemic issues in the provision of healthcare for those dealing with LC, where demand appears to outstrip available resources.

Conclusions

To conclude, the findings highlight significant challenges in managing LC, both at the individual and healthcare system levels. The unpredictable, wave-like fatigue described by participants severely disrupts daily life. For healthcare providers, this fluctuating

fatigue complicates diagnosis and treatment, which emphasises the need for comprehensive care, including rehabilitation and mental health support.

Moreover, participants' struggles to access healthcare reveal systemic limitations within the NHS. The inability to secure timely appointments, as described by Amy and Catrin, points to an overstretched system unable to meet the needs of LC patients. This has broader implications for healthcare policy, underscoring the urgent need for increased resources and infrastructure to address chronic post-COVID conditions. Delayed care can worsen symptoms and disproportionately affect individuals with pre-existing conditions, further straining the healthcare system.

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