



The curious incident of long COVID symptoms, from an imaginary condition to a recognised syndrome: a “small victory”

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Received: 28 March 2022
Accepted: 19 April 2022

To the Editor:

Over the past 2 years, the scientific community has acquired a better understanding about coronavirus disease 2019 (COVID-19) as an acute disease, but there is still much to learn, especially when considering the chronic aspects of this illness. In the early stages of the pandemic, healthcare workers focused on acute COVID-19 symptoms, often overlooking its long-term and chronic implications. In October 2021, the World Health Organization recognised these long-term complications as long COVID syndrome, which probably affected more than 62% of patients [1]. Patients with long COVID syndrome experienced the fear of living forever with those symptoms, arising from the lack of medical information on this issue [2], combined with the feeling of being ignored and disbelieved. Several patients felt they did not have access to appropriate healthcare, as they perceived that healthcare workers disregarded their symptoms and judged them as unreal, often considering them secondary to psychiatric issues [3].

Beyond the healthcare field, patients found little support or understanding, even in their social networks, with a post-COVID syndrome resulting in a deterioration in their ability to perform daily activities, family relationships and working capacity [1]. For instance, family members were frequently unable to provide enough emotional support or accept the patient's increased need for rest due to symptoms [2]. In the workplace, people were often unable to perform their duties as well as usual, thus worked shorter shifts due to fatigue and a fear of making mistakes caused by brain fog [3]. This led to isolation, anxiety, self-doubt, changed professional identity [3, 4], and to a dangerous feeling of loneliness.

Originally these “invisible symptoms” seemed to be noticed only in online communities which reported symptoms primarily through anecdotes. Patients' illness narratives drew public and scientific/medical attention to long COVID syndrome, leading to the recognition of long COVID symptoms as a physical illness rather than an imaginary condition [4]. This belief and attention by clinicians and relatives provided patients with a sense of relief and recognition, which can be defined as “a small victory” [3]. Long COVID syndrome is consistently regarded as the first disease collectively constructed and identified by patients [5].

The impression of being understood and believed is particularly important for patients, as illness makes people feel vulnerable and in need of assistance. Such debilitating conditions put patients in a position of dependence on healthcare workers, fostering the activation of a set of defence mechanisms, unconscious strategies used by our mind to protect the ego from stress, fear or trauma. One of the most used during illness is the so called “regression”, in which an individual, regardless of age, copes with stressful situations by retreating to earlier stages of development and abandoning forms of gratification appropriate to them. For example, an adult who is hospitalised after being diagnosed with a medical issue may deal with their circumstances by curling up on the bed in the fetal position and clutching a stuffed animal dog. A reversible regression is an important adaptive tool during illness. In the short term, it may have a positive function by helping patients to accept the conditions imposed by illness, but it may hinder their independence and empowerment in the long term. Indeed, the patient–clinician relationship could easily activate reversible mechanisms, which are frequently expressed in terms of dependent child and caring/rewarding parent [6]. Consistently, healthcare workers' recognition and acceptance of symptoms are critical in this field.



Shareable abstract (@ERSpublications)

In the early stages of the pandemic, patients with a post-COVID condition felt ignored and disbelieved by their doctors and relatives. Given the importance of the doctor–patient relationship in post-COVID management, we recommend “relationship-based care”. <https://bit.ly/3vQ9RO1>

Cite this article as: Di Mattei VE, Perego G, Milano F, *et al.* The curious incident of long COVID symptoms, from an imaginary condition to a recognised syndrome: a “small victory”. *Eur Respir J* 2022; 59: 2200653 [DOI: 10.1183/13993003.00653-2022].



In addition, the literature shows that the attachment styles of patients and healthcare workers influences their relationship [7]. Attachment styles are different ways of interacting and behaving in intimate relationships, which are heavily influenced by self-worth and interpersonal trust. Theoretically, the degree of attachment security in adults is directly related to how well they bonded to others as children. Interestingly, patients' attachment style influences their health-seeking behaviours as well as their acceptance of being helped and cared for [8]. This is also relevant for healthcare workers, as attachment style influences their ability to communicate well with the patient and not only get a more complete understanding of the disease but also build a solid patient–doctor relationship [7]. However, the effort of being empathetic and open to the patient's experience may be hampered by the medium and high burnout levels measured among physicians and nurses, especially as was noticed during the pandemic [9].

In conclusion, given the importance of the doctor–patient relationship in long COVID management, we advocate for a “relationship-based care” [10]: general practitioners must offer consideration, empathy and support to long COVID patients and their families, to assist them in overcoming the disease.

Moreover, several studies recommend face-to-face patient assessment and the adoption of a multidisciplinary approach at each stage of the disease [2, 3]. This would involve the integration and training of mental health professionals and occupational health teams, which could help reduce burnout among physicians and nurses, while also allowing for continuity of care and personalised rehabilitation.

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Conflict of interest: The authors declare they have no conflict of interest.

References

- 1 Harari S, Ripamonti L, Marveggio P, et al. Long COVID: a patient perspective. *Eur J Intern Med* 2022; 95: 104–105.
- 2 Kingstone T, Taylor AK, O'Donnell CA, et al. Finding the “right” GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open* 2020; 4: bjgpopen20X101143.
- 3 Callan C, Ladds E, Husain L, et al. “I can't cope with multiple inputs”: qualitative study of the lived experience of ‘brain fog’ after Covid-19. *MedRxiv* 2021; preprint [<https://doi.org/10.1101/2021.08.07.21261740>].
- 4 Baz S, Fang C, Carpentieri JD, et al. Understanding the Lived Experience of Long Covid: A Rapid Literature Review. (Convalescence Long-COVID Study Briefing Reports). London, University College London, 2021.
- 5 Callard F, Perego E. How and why patients made Long Covid. *Soc Sci Med* 2021; 268: 113426.
- 6 Kernberg OF. Severe Personality Disorders: Psychotherapeutic Strategies. New Haven, Yale University Press, 1984.
- 7 Ardenghi S, Rampoldi G, Bani M, et al. Attachment styles as predictors of self-reported empathy in medical students during pre-clinical years. *Patient Educ Couns* 2020; 103: 965–970.
- 8 Hooper LM, Tomek S, Newman CR. Using attachment theory in medical settings: implications for primary care physicians. *J Ment Health* 2012; 21: 23–37.
- 9 Di Mattei VE, Perego G, Milano F, et al. The “healthcare workers' wellbeing (Benessere operatori)” project: a picture of the mental health conditions of Italian healthcare workers during the first wave of the COVID-19 pandemic. *Int J Environ Res Public Health* 2021; 18: 5267.
- 10 Atherton H, Briggs T, Chew-Graham C. Long COVID and the importance of the doctor–patient relationship. *Br J Gen Pract* 2021; 71: 54–55.