

Abstract

Background: Long COVID remains a new and emerging syndrome within the healthcare and scientific communities with various definitions and ongoing efforts to better understand therapeutic options. This syndrome has widespread and variable impacts on patients, so it is important to identify and address patients' experiences with the syndrome to optimize care and support for those affected.

Objective: The objective of this review is to examine the current literature on patient experiences with Long COVID and provide a representative overview of the main themes that arise from these experiences.

Methods: A comprehensive literature review was conducted. The search was restricted to publications from 2021 to 2024, and included keywords such as, "Long COVID," "stigma," and "patient experiences." This initial search yielded 95 articles, which were then evaluated for content relevance and alignment with the study objectives. This yielded a set of 15 papers for further review and thematic extraction.

Results/Discussion: Three main themes were identified through this review: Social stigma, health inequities/barriers to care, and epistemic injustice. Social stigma, driven by fear and lack of understanding, was highly prevalent among patients with Long COVID. These patients face specific barriers to care, including long wait times, few providers comfortable managing Long COVID, and limited disease-specific resources. Long COVID also disproportionately impacted underserved communities, highlighting health inequities stemming from structural racism and occupational segregation. Epistemic injustice, particularly testimonial and hermeneutical injustice, was prevalent among Long COVID patients. Patients experience isolation and invalidation due to a lack of knowledge, systemic underrepresentation, and symptom dismissal. Studies discuss several strategies to address systemic inequities and improve patient care.

Conclusions: Overall, this review highlights the need for further understanding of Long COVID, greater empathy and validation of patient experiences, and systemic change to optimize care for these patients.