PATIENT EXPERIENCES OF CARE FOR LONG COVID

A Narrative Review

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Introduction

Post Acute Sequelae of COVID-19 (PASC), or "Long COVID," is a new and emerging syndrome with evolving definitions and limited therapeutic guidance.

Current Initiatives

- The US National Academies of Science and Medicine (NASEM) has released a report to establish a common clinical definition
- RECOVER research program
- AHRQ Long COVID Care Network (primary-to-specialty care integration)

Study Rationale

- Patient Advisory Board (PAB) members identified stigma as a key barrier to accessing care
- Clinician awareness, knowledge, and attitudes often lag behind patient needs in emerging syndromes
- Understanding the patient experience is critical to informing clinicians, researchers, and policymakers

Results

Theme	Core Issues	Patient Impact	Improvement Strategies
Social Stigma	• Fear of contagion • Poor understanding • Lack of objective biomarkers • Clinician stigma	• Isolation • Anxiety and/or depression • Reduced quality of life	• Validation of experiences • Recognize bias • Clinician education
Health Inequity	• Structural racism • Occupational segregation • Long wait times • Limited healthcare access	• Disproportionate burden • Delayed or fragmented care	• Multi-disciplinary care approach • Increasing access to specialist care
Epistemic Injustice	• Dismissal of symptoms and experiences • Lack of diagnostic clarity	• Invalidation • Loss of trust in healthcare • Lack of support	• Active listening • Removal of patient blame • Clinician engagement despite uncertainty

Objective

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

Methodology

- Literature review conducted via PubMed (2021–2024)
- Keywords: "Long COVID," "stigma," "patient experiences"
- 95 articles identified; screened for relevance and alignment with study objectives
- 15 articles selected for full-text review and thematic extraction
- Articles categorized into three themes: social stigma, health inequity, and epistemic injustice

Discussion

- Social stigma, health inequity, and epistemic injustice are deeply interconnected and mutually reinforcing
- Stigma discourages care-seeking and compounds existing health inequities, particularly among underserved communities
- Health inequities create conditions for epistemic injustice, as marginalized patients are more likely to have symptoms dismissed or invalidated
- Epistemic injustice perpetuates stigma by reinforcing the notion that Long COVID is not a legitimate condition
- This cycle isolates patients and erodes trust in care — systemic, patient-centered approaches are needed to interrupt it

Limitations

- Selected articles are not exhaustive; findings represent a representative rather than comprehensive overview
- Search terms were intentionally narrow, which may have excluded pertinent studies using different terminology
- Rapid evolution of Long COVID literature means some relevant findings may have emerged after the search period (2021–2024)

Conclusion

Overall, this review highlighted the need for further understanding of Long COVID, as well as the need for more empathy and validation of patient experiences with Long COVID. The review also highlighted the need for systemic change to optimize care for these patients.

References

Scan the QR Code for list of references.

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Conflict of Interest

The authors have no conflicts of interesr to disclose.