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Title

“It All Revolves Around the Pain”: Patient Experiences of Navigating Care for Long COVID Pain Symptoms

Priority 1 (Research Category)

COVID-19

Presenters

Rachel Geyer, MPH, Kris (Pui Kwan) Ma, PhD, Jing Zhang, Nicole Gentile, MD, PhD

Abstract

Context: Persistent pain is experienced among nearly half of the patients with long COVID (LC). However, pain associated with LC has not been well understood and there are no current standardized treatments.

Objective: To document the lived experience of patients with LC pain, including how they access and receive healthcare, to improve services for LC pain evaluation and treatment.

Study Design: We conducted seven semi-structured focus groups with 25 adult patients who had a positive COVID test, reported pain as one of their primary LC symptoms at intake, and were seen in the University of Washington Long COVID Clinic for at least one visit between June 2021 to February 2023.

Population Studied: The diverse sample included patients with LC with different insurance/payor types, and developed COVID symptoms at various time points in the pandemic.

Dataset: Focus group questions involved assessment of experience with pain symptoms, patient-provider interactions, and LC diagnostic and treatment process. Demographic characteristics and the Patient-Reported Outcomes Measurement Information System (PROMIS) pain interference measure were collected via surveys.

Results: Participants were predominantly female (n=16, 64%), non-Hispanic (n=17, 68%), White (n=10, 40%), and living in urban areas (n=23, 92%). Under half the participants reported working full-time (n=12, 48%). Insurance types included private (n=12, 48%), Medicare/Medicaid/Public (n=8, 32%), Worker’s compensation (n=2, 8%), and other (n=3, 12%). Thematic analysis identified key themes in the following domains: 1) patients’ pain interacts with other LC symptoms, 2) there is a lack of formal recognition for LC, 3) frustrations exist with the lack of resources in healthcare and social systems for LC,

4) patients value being heard and having their experiences validated by clinicians, 5) treatment recommendations are not well aligned, 6) what has worked thus far, and 7) patients demonstrated resilience and use of various coping strategies.

Conclusions: Long COVID pain is prevalent, and if left untreated can develop into more debilitating pain conditions, disability, and mental health comorbidities in an already vulnerable population.

Recommendations for optimizing care include adopting a whole-person care approach, listening and validating patients' lived experiences while acknowledging evolving evidence, and improving coordination of care.

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