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Title

Primary care patient experiences seeking healthcare for long-covid: A qualitative study

Priority 1 (Research Category)

Qualitative research

Presenters

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Abstract

Context: Almost 100 million Americans have been infected with SARS-CoV-2, and an estimated 9 to 27 million of those individuals will experience unpredictable long-term symptoms across the body and mind. Current evidence on Covid-19 and long-Covid has focused on hospitalized patients, overlooking the crucial role of primary care in health.

Objective: Our study aims to capture primary care patients' experiences navigating healthcare with a novel and debilitating condition.

Study Design/Analysis: We used a phenomenological approach to explore primary care patients' experiences living with long-Covid. Patients were recruited from a long-Covid triage clinic. Eligible patients were 18+ years old and experienced long-covid symptoms for 12 or more weeks. Data collection occurred through semi-structured in-person or telephone interviews, which were recorded and transcribed verbatim.

Setting: Academic medical institution in the Mountain West.

Outcomes: Patient experiences navigating the healthcare system.

Results: 42 eligible participants were contacted, and 20 participated in interviews (48% response rate). Three themes emerged from the interviews: (1) patient expectations, (2) patient experiences, and (3)

accessing care. Patient expectations were categorized as expectations for primary care providers (PCPs) and expectations for treatment. Generally, patients are expected to be listened to and treated as an individual with unique health histories and expected clear communication from different members of their care team. Patient experiences and expectations did not always align. Some patients had positive experiences with PCPs and other specialists, while others felt dismissed and struggled to coordinate care. More specifically, accessing appropriate and timely care was challenging for several patients. Patients often waited several months before seeing a specialist or participating in tests while symptoms generally worsened or remain the same. Problems accessing timely and appropriate care also impacted how much patients paid for care, and a lack of communication between a patient's care team and insurance companies delayed care further.

Conclusion: Patients expect to be involved in knowledge creation and sharing with physicians in many specialties to further understand and explore treatment options for PCC. Guidelines for diagnosing and treating PCC in primary care should be longitudinal and should facilitate care coordination.