Mapping long COVID-19 patient journeys for rheumatic disease patients

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BACKGROUND

- As the COVID-19 pandemic continues, there is increased need for health care services to address the needs of patients who develop persistent 'long COVID' symptoms.
- One-third of individuals who contract COVID-19 develop 'long COVID'.
- Underlying health conditions like rheumatic diseases (RDs) increase long COVID risk, with 37% of RD patients reporting symptoms at 6 months.
- Long COVID related issues (e.g. fatigue, chronic pain, respiratory and neurological symptoms) impair physical and mental functioning and reduce quality of life.
- We aimed to describe care pathways and care coordination challenges for patients with rheumatic diseases and long COVID.

METHODS

- From a registry of rheumatology patients with a confirmed COVID-19 diagnosis at our institution, we identified 16 patients with persistent COVID-related symptoms ≥3 months after symptom onset.
- The study team closely read electronic medical record documents and created patient journey maps summarizing health status, interactions with health care providers, treatments, and decision making over time.
- We assessed severity of symptoms thought to be associated with COVID-19 using the WHO Clinical Progression Scale (CPS) during hospitalizations and the Post COVID Functional Status (PCFS) scale at other times, and changes in health status over time were visually represented based on changes in the CPS and PCFS on the patient journey maps.
- Care coordination challenges were documented and described.

RESULTS

- Subjects were aged 27-70, with 10 female and 6 minority patients out of 16. 9 out of 16 were employed full time.
- 13/16 were hospitalized for COVID related issues. Duration of COVID-related symptoms ranged from 3-13 months, with 9/16 having continued symptoms at last documented record.
- An excerpt from a patient journey map is shown in **Figure 1**.
- We identified 5 categories of care coordination issues: management of disease flares/rheumatic disease medications, work-related issues, access to care, patient requests for COVID-19-related treatments/procedures, and patient need for reassurance/information. Examples are presented in the form of illustrative **Vignettes 1-4**.

CONCLUSION

- Among patients with rheumatic disease, long COVID cases demonstrated variable trajectories and disrupted patients' functioning and ability to work.
- Long COVID can be frustrating for patients, as it can cause symptoms which are new, often have no clear explanation, and require follow-up from multiple specialty providers.
- Providers are confronted with the challenge of disentangling long COVID symptoms from those caused by patients' rheumatic disease or other comorbidities.
- Patients relied on assistance from health care providers to legitimize requests for work leave and working conditions that would reduce their risk of exposure to COVID-19.
- The care coordination issues identified remain broadly relevant at this point in the pandemic, and can be used to establish priorities for research/policy around long COVID both for patients with RMDs and other chronic illnesses.

A patient hasn't been able to work since getting COVID-19 a few months ago. She sends a plea for help to her rheumatologist: "What is my diagnosis? What is my treatment plan?"

Figure 1. Excerpt from a patient journey map

Day	1	11	13	16	17	20	24	25	27	27	27	28	28	41
Event description	Symptom onset.	Symptoms continue, patient visits urgent care and is tested for COVID-19.	Urgent care calls patient to inform about positive COVID-19 test.	Family medicine (PCP) calls patient to see how she is doing.	Sabrina calls family medicine to speak with a doctor	Urgent care calls Sabrina to follow up on her COVID symptoms	Virtual visit with family medicine	Sabrina messages PCP to ask some questions	Virtual visit with family medicine	Sabrina goes to urgent care (respiratory clinic) for further workup	Urgent care messages Sabrina with chest Xray results	Sabrina messages urgent care requesting chloroquine and hydroxychloroquine for her COVID symptoms	Sabrina messages PCP requesting chloroquine and hydroxychloroquine for her COVID symptoms	Virtual visit with cardiologist (referred by PCP)
Health status better ↕ worse	Mild cough	Sore throat, cough, yellow mucous, chest congestion, ear pain, chills, low fever. Tested positive for COVID-19.	Intermittent abdominal pain, nausea	Chills, cough, headache. Has "good and bad days"	Stuffy head, diarrhea, headache	Nausea, occasional vomiting, abdominal pain, cough, congestion	Abdominal pain and nausea. Unable to eat well, has been losing weight. mild dyspnea. Rash on abdomen.	Coughing, worsening chest pain, lungs feel 'airless', fatigue, unexplained bruising	Chest pain, pain when coughing, chest tightness, difficult to take deep breaths	Lungs hurt, sinus issues, difficulty breathing	Chest Xray normal			Chest pain and worsening dyspnea. Slower pace running on treadmill. Out of breath walking up stairs
Patient needs/ emotions								Sabrina wants to know if she should be concerned about her lab results. She requests chest CT as discussed, and asks for medication to help her return to 'normal'	Sabrina is worried whether symptoms due to asthma, COVID-19, or pneumonia	Sabrina has not been able to exercise normally. Ran on treadmill yesterday and feels worse today.	Sabrina asks about the discrepancy between her previous CT scan showing diseased areas in lungs and the chest Xray which appears normal. Does she still have COVID-19 and will her prescribed medication heal the diseased part of her lungs?	Sabrina is concerned about the duration of her COVID-19 symptoms and doesn't want to die	Sabrina is concerned about the duration of her COVID-19 symptoms and doesn't want to die. Needs reassurance.	
Event setting	Home	Outpatient clinic	Home phone call	Home phone call	Home phone call	Home phone call	Home video call	Patient portal	Home video call	Outpatient clinic	Patient portal	Patient portal	Patient portal	Home video visit
Provider(s)		Urgent care	Urgent care	Family medicine	Family medicine	Urgent care	Family medicine	Family medicine	Family medicine	Urgent care	Urgent care	Urgent care	Family medicine	Cardiology
Provider actions **-decisions** **-procedures** **-referrals** **-treatment changes**		COVID-19 and flu tests performed.	Counseled about quarantine and isolation for family members. Patient should call doctor if symptoms worsen or go to ER if symptoms become severe.		Video visit scheduled with PCP.	Since patient is now under care of PCP, Urgent care will close her case for further management.	Refilled asthma inhaler. Rash might be due to RMD; ordered bloodwork for upcoming rheumatology appointment and will consult dermatology. Will order chest CT if respiratory symptoms worsen	Scheduled video visit	Follow up same day in respiratory clinic (urgent care) for further workup and exam	Chest Xray Amoxicillin-clavulanate for sinusitis Prednisone for dyspnea Return if symptoms worsen	Provider responds that COVID-19 could still be contributing to Sabrina's lung symptoms. For the previous CT scan, the diseased areas should resolve on their own with time.	Provider forwards her message to PCP and informs them of yesterday's visit and decisions.	PCP calls Sabrina. Explains that the requested meds are not currently recommended for outpatient treatment. Discusses her fears about COVID diagnosis and recommends decreasing watching news coverage.	Recommends she go to ER for further evaluation for pulmonary emboli vs. pericarditis/myocarditis. Could be due to COVID-19 or lupus.
Challenges & opportunities for improvement						Good that Urgent care followed patient when they thought she had no PCP. Perhaps they should have communicated with her earlier about whether she had a PCP, to avoid duplicating follow-up.	Unclear if abdominal pain and nausea due to COVID or recent gall bladder removal.	Patient frustrated with triage procedures, prefers in-person visit but is only able to schedule video visit			Patient is confused by discrepancies between current and previous imaging results and implications for her COVID-19.	Patient requests treatments that are not effective for COVID-19	Patient requests treatments that are not effective for COVID-19	Unclear if symptoms due to COVID-19 or rheumatic disease.

Vignette 1: Disease flares/DMARD management

A patient has several months of increased joint and muscle pain post-COVID-19, but it is unclear whether the cause is their rheumatic disease, COVID-19, or something else.

The patient is a woman in her 60s with lupus, polymyalgia rheumatica, fibromyalgia, and diabetes. She has chronically elevated ESR/CRP that does not respond to steroids. She tested positive with COVID-19 seven months ago. Since then, she has continued to have dyspnea and respiratory symptoms, difficulty swallowing, and memory problems.

Today she has constant pain which started 4 months ago and has been getting worse. The pain moves from one area to another (e.g. sometimes legs, sometimes shoulders). Her morning stiffness lasts for 30 minutes, and she has numbness in her hands at night. Many tender spots in muscles and joints were found on exam.

Her current medications are prednisone, gabapentin, and tramadol.

The rheumatologist determines that her flaring pain symptoms are due to fibromyalgia rather than inflammation. Management is deferred to her PCP. The rheumatologist discusses cannabinoids as a possible treatment option which may be safer than opioids.

Vignette 2: Work related issues

Throughout the pandemic, a patient has turned to his providers for documentation to support him in requesting sick leave and advocating for safer working conditions for himself.

The patient is a man in his 20s with psoriatic arthritis. His work involves close contact with people, which concerns him because he takes an immunosuppressive medication which increases his vulnerability to infections.

The patient became ill with COVID-19 twice: the first time his symptoms required 6 weeks off work, and the second time he needed a month off work. Both times his symptoms were severe enough to bring him to the emergency department. Documentation of the severity of his illness was needed from his employer's human resources department for extended leave—specifically, the provider was asked to explain the nature of his immunocompromised condition and how this would affect his ability to perform work duties, in order to grant a work accommodation under the Americans with Disabilities Act.

The patient has also asked his rheumatologist for letters to support his request for working conditions that would reduce his risk of infection as an immunocompromised individual during the pandemic. Before getting COVID-19, the patient obtained a letter requesting that he be allowed to work from home during the outbreak because he takes immunosuppressive medication. After recovering from his first COVID-19 illness, the patient was worried about exposure to COVID-19 when he returned to work, and requested another letter from his rheumatologist stating that he could safely return to work provided he could maintain 6 feet of distance to clients, and not be required to do activities bringing him closer than 6 feet to clients.

Vignette 3: Patient need for reassurance/information

A patient is frustrated by persistent debilitating COVID-19 symptoms and wants a medical explanation for their symptoms.

The patient is a woman in her 40s with history of asthma and a previous diagnosis of lupus, but no current symptoms consistent with active lupus. It has been 50 days since her COVID-19 symptoms started. She has been unable to return to work since getting COVID-19.

Her current symptoms are: dyspnea, chest pain, nausea, vomiting, fatigue, bone pain, aching joints, back pain, stiff neck, difficulty walking, eye pain, headaches, paresthesias, dizziness, and short-term memory problems. She was previously physically active, but developed muscle pain after trying to go jogging again recently. She gets out of breath walking up stairs.

The patient has had appointments with urgent care, family medicine, cardiology, and rheumatology to address her ongoing COVID-19 symptoms. She was recently referred to the emergency department to evaluate possible pulmonary emboli/pericarditis/myocarditis, but no signs were found.

The rheumatologist believed some of her COVID-19 symptoms were consistent with fibromyalgia and has discussed possible treatments with her and shared information about fibromyalgia. Home exercises were recommended for her hand and knee arthritis.

Today the patient sends a message to the rheumatologist asking for a diagnosis and treatment plan. The rheumatologist responds, reiterating that the symptoms do not seem to be due to lupus, but may be due to hand and knee arthritis and related to fibromyalgia. The patient responds expressing her frustration with not knowing the cause of her ongoing symptoms.

Vignette 4: Access to care

A patient is reluctant to attend in-person visits due to fear of reinfection with COVID-19.

The patient is a man in his 50s with relapsing polychondritis. He got COVID-19 a month ago and was admitted to the hospital for acute respiratory failure. He had pulmonary emboli and deep vein thrombosis. His rheumatic disease medications included infliximab, methotrexate, and methylprednisolone; his rheumatologist ordered that he stop infliximab and methotrexate until he recovers from COVID-19. He was discharged home a week later, and has been taking leave from work to recover at home. He was discharged with an oxygen tank for supplemental O2.

Five days ago, he tripped on his oxygen tank and injured his wrist. He visited his primary care provider and had an X-ray, which showed the wrist was fractured. He did not receive a cast and has been keeping his wrist wrapped in an Ace bandage.

Today he was scheduled for in-person follow up at an orthopedic clinic, but he contacted the clinic asking if it is necessary for him to come in person or if he can have a video visit instead. He is worried about being exposed to COVID-19 in the clinic, since he is immunocompromised. The clinic staff convince him that he needs to come in for examination of his wrist and fitting of a wrist splint.

FORWARD
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