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“Healing Can Be a Very Jagged Line”: Reflections on Life as a COVID-19 Long Hauler

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Abstract

“Long COVID” — a term referring to COVID-19-associated symptoms and conditions (ie, sequelae) that remain or emerge after resolution of a SARS-CoV-2 infection — is a multifaceted condition about which little is known. As part of formalized patient-engaged research at a large Midwestern health system, patient stakeholders with long COVID (N=5) wrote stories based on their lived experience, as this was their preferred format for detailing their experience with the condition. These patient stakeholders reviewed one another’s stories, identified relevant quotes, and provided opportunities for elaboration. Independently, a trained researcher extracted quotes from the stories, identified themes, and wove the quotes together to share the independent, yet similar, stories. Emergent themes were that of uncertainty about the symptomatology of long COVID and its effects on patients’ mental health, physical functioning, family unit, self-identity, and future outlook. Further patient-engaged research on understanding the lived experience of long COVID may serve to advance knowledge and treatment. Health care providers caring for those with long COVID can benefit from listening and validating the stories of individuals suffering from this condition. (*J Patient Cent Res Rev.* 2023;10:77-81.)

Keywords

COVID-19 pandemic; post-acute sequelae; PASC; long hauler; SARS-CoV-2; patient-engaged research

In the United States alone, more than 91 million cases of COVID-19 have been reported through August 2022.¹ COVID-19’s symptomatic effects vary drastically from one individual to another. The occurrence of post-acute sequelae of SARS-CoV-2 infection (PASC), more commonly referred to as “long COVID,” is a crippling aftermath of the pandemic, with 10%–30% of patients diagnosed with COVID-19 reportedly continuing to experience symptoms after their infection period is over.^{2,3} These symptoms, which may include fatigue, shortness of breath, “brain fog,” sleep disorders, fevers, gastrointestinal symptoms, anxiety, and depression, can persist for months or years and can range from mild to incapacitating.² There is uncertainty regarding which risk factors might predict who will develop long COVID as well as how to alleviate its symptoms.⁴ Consequently, there is limited information on the impact of long COVID on a patient’s quality of life and how best to approach treatment from a patient-centered standpoint. Moreover, the number of people affected by COVID-19 is unprecedented, and although the magnitude of long

COVID remains unknown, given the diverse number of individuals who have been or will be infected with SARS-CoV-2, the public health impact of long COVID could be profound.⁵

Henry Ford Health, located in Detroit, Michigan, a COVID-19 hotspot at the time of this writing,⁶ is an integrated health system that provides care and wellness services across diverse communities. The mission of Henry Ford’s Patient-Engaged Research Center (PERC) is to translate the patient voice into evidence-based care through community engagement and research methods. PERC relies on active participation of patient advisors in its Patient Advisor Program, individuals who contribute their patient or caregiver experience and feedback to projects and initiatives to ensure delivered care is patient-centered.⁷ Many PERC patient advisors are members on Henry Ford’s patient and family advisory councils (PFACs), for which patient advisors, together with health system staff, “collectively drive meeting agendas by identifying priorities and topics they would like to focus on” or that are important to them.⁷ The COVID Recovery Care PFAC was formed in Fall 2021 to create an opportunity for “COVID long haulers” to become partners with researchers and clinical providers as a means of informing knowledge gaps in treatment and care and to highlight the voice and experiences of these patients.

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The National Institutes of Health recently brought together more than 1200 expert stakeholders, including researchers, clinicians, and affected community members, to discuss what is known about long COVID and the knowledge gaps that need to be addressed in future research. The major takeaway: “Research efforts will need to involve a collaboration among clinicians, researchers, advocacy groups, and patient communities.”²⁴ The purpose of this paper is to highlight such a collaboration between researchers and patients. Stories written by patient advisors from the COVID Recovery Care PFAC have been analyzed collaboratively to address potential knowledge gaps and align research focus accordingly.

METHODS

During monthly PFAC meetings, patient advisors continuously expressed a need to tell their long COVID stories. Specifically, patient advisors discussed wanting their stories disseminated to a larger audience — as part of an advisor’s role is being an advocate for other patients. Based on these discussions, PFAC facilitators (D.M. and S.S.) sought dissemination options and brought these ideas back to the PFAC for consensus. The idea of publishing a paper as a group was deemed most appealing, as patient advisors felt it would reach a large audience, including researchers and clinicians (targets of interest). A study design was determined collaboratively and included within a larger institutional review board protocol encompassing the work of patient advisors at Henry Ford.

To begin, patient advisors participated in a writing exercise to develop their individual stories, reflective

of their lived experience with long COVID (Table 1). An exercise outline was ultimately created by PFAC facilitators (D.M. and S.S.) and contained the following sections:

- **Section 1 — *Life before COVID-19 (“a day in the life”)*.** In this section, patient advisors were asked to share about their lives before they were diagnosed with COVID-19. Specifically, patient advisors shared what their regular or typical routines were like and what their emotional and physical state was before they contracted COVID-19.
- **Section 2 — *COVID-19 diagnosis*.** Patient advisors were asked to elaborate on their experience of being diagnosed with COVID-19. This included what feelings and emotions they had at the time of their original diagnosis.
- **Section 3 — *Life as a long hauler*.** Patient advisors were asked to discuss themes/elements of importance that were derived in previous PFAC meetings. This included, but was not limited to, their symptoms, their “new normal,” the biggest change impacting their life (eg, feeling/emotions, mental/mind, body, relationships), and their struggles/difficulties.
- **Section 4 — *Hopes for future*.** In the fourth and final section, patient advisors were asked to share what their hopes were for the future. This section allowed them to reflect on what their future self will feel like, physically, mentally, and emotionally. This also gave patient advisors a chance to share what they hope will be treatment options for long COVID symptoms in the future.

Table 1. Project Part 1 (Writing Prompts) and Part 2 (Review Prompts)

Writing prompts – Part 1	
Section 1	Life before COVID-19 (“a day in the life”)
Section 2	Your COVID-19 diagnosis
Section 3	Life as a long hauler: <ul style="list-style-type: none"> A. Symptoms B. Your “new normal” C. Biggest change that has impacted your life <ul style="list-style-type: none"> o Feeling/Emotions o Mental/Mind o Body o Relationships D. Struggles/Hardest part
Section 4	Hopes for future
Writing exercise – Part 2	
Review & comment on other stories	<ol style="list-style-type: none"> 1. Note any similarities/differences compared to your own long COVID story. 2. Was there anything you wanted to know more of about their journey? 3. Any questions for the author? 4. Overall comments/feedback:

D.M. emailed the exercise outline and created a shared folder for stories to be saved and shared. Patient advisors were given 2 months to complete their short story. After completing their stories, participants were asked to read and provide feedback on another patient advisor's story. To help guide the feedback, when reviewing each other's stories, patient advisors were asked to highlight similarities and differences in their own story and were allowed to ask questions and make additional comments to their fellow advisors. The initial process of reviewing only one patient advisor's story was expanded so all members could review one another's stories based on feedback that the patient advisors enjoyed exchanging, reading, and providing feedback to each other.

Members of the research team took the lead in abstracting quotes for this paper. L.H. identified symptomatology relevant to COVID-19 along with the impact of long COVID on measures of functioning. Abstracted quotes were woven together in a story format, which S.S. and D.M. then reviewed. Clinical implications were distilled by L.H. and S.S. The final draft of the paper was shared with the patient advisors, who were given time to respond with feedback and edits. Ultimately, patient advisors gave the final approval before submission and those who provided their stories are co-authors on this manuscript.

Notably, as our goal was to elevate the patient stakeholder stories, we used a qualitative conceptual framework to extract themes from the 5 stories. However, we did not use strict qualitative research methods or employ a sample size from which data saturation would be achieved.

RESULTS

Of the 11 patient advisors in the COVID Recovery Care PFAC, 5 participated in the writing exercise to share their story (R.A., D.D., D. R., M.N.W., and J.W.). Many of the stories began by discussing life before COVID-19, how/when it was contracted, COVID-19 symptoms, and the long COVID sequelae they have experienced. As noted in Methods, all patients who participated in the writing exercise read, provided feedback/insights/questions, and highlighted quotes or sections that related to their own experience. Independent of this process, a researcher (L.H.) extracted quotes from the stories, which clustered in 5 areas: mental health; physical functioning; family unit; self-identity; and outlook for the future. Select quotes are included within this section to contextualize these areas.

Symptomatology and Contracting COVID-19

For most, the onset of COVID-19 was insidious, with a few isolated symptoms that continued to progress. A nurse wrote about contracting COVID-19 at the start of the pandemic in March 2020: *"My exposure occurred a*

couple of days before masks were mandated. My taste and smell abruptly and completely disappeared (early on, that symptom wasn't even one of the 'criteria')." She sought follow-up care and *"was met repeatedly with 'we just don't know' and 'it's a new virus — it's a mystery.'"*

Many reflected on the exhaustion that they felt: *"I knew what tired was, but this was different."* Others got sick just as vaccines were being released in December 2020 or saw a change in their symptoms with the vaccine. *"After that second dose I started to have more 'good days' than 'COVID days.'"* Before that, *"I was still having severe brain fog, fatigue, migraines, depression, and joint pain."* But the symptoms continued to linger. Another wrote, *"I have moments of total memory lapse."*

To combat this, some resorted to tracking their own symptoms: *"I started to test my cognitive function on my own by using sudoku puzzles. On what I would consider a 'good day' I would be able to do a level 3 puzzle, but on my 'COVID days' I wouldn't even be able to complete a level 1 puzzle. It validated what I already suspected, some days my cognitive ability was diminished."*

Changes in Physical and Mental Health Functioning

Life changed in many substantial ways for those dealing with long-haul symptoms. It meant needing to leave their jobs, scale back their hours, and give up activities they once enjoyed. *"I am always doubting if I will be able to do something without experiencing the ramifications of having COVID."*

This comes with learning their physical limitations: *"I am becoming better at recognizing when I need to stop, step back, or take a breath."* Another wrote, *"I have a lot of fear surrounding exercise, because it is the one thing I know consistently triggers my symptoms."* And the ramifications can be severe: *"I have parameters, and if I push too hard, I end up in the hospital."*

For some, mental health struggles emerged. It [COVID] *"affects my mental health more than anything, which then makes everything worse for me again and it is just a terrible cycle to be in."* Another wrote, *"My new 'normal' 2 years later still consists of a nightstand full of medications (several supplements, 3 cardiac meds, 2 inhalers, and meds to help the depression and anxiety this has all caused)."*

Living with long COVID also means being more aware of triggers: *"I must be careful not to allow my mind to go all over the place. It becomes a constant of not worrying about what you hear on the news or see on movies dated before COVID-19 about 'viruses.'"*

Long COVID and the Family Unit

Several people reflected that although they were the ones who contracted COVID, it affected the entire family unit: *“This has been the hardest part of all of this for me, is what it is doing to my family because of what I can’t do anymore. I have always hated saying ‘no,’ especially to my kids when they want to do something, but I have had to more than ever over the last year and a half.”* Others echoed similar challenges, *“My stepdaughters don’t understand why I can’t play soccer in the yard with them anymore or run alongside them while they ride their bikes.”*

Yet, family also became a source of support as the symptoms continued: *“During COVID-19 my marital relations got better. The thought of the worse happening united us closer together.”*

Self-Identity

Researchers now know that being vaccinated does not offer full protection against COVID-19 variants, and those who were previously infected are still at risk for re-infection, stoking fear among many COVID-19 long haulers: *“I have never felt exactly like my pre-COVID self. I still experience a lot of fear and anxiety about getting COVID again.”* Others lost a sense of who they are: *“Before I contracted COVID, I thought of myself as a smart, focused woman who could multitask, hold intelligent conversations, and was good with numbers. Since COVID, I don’t feel like that anymore. I feel broken.”*

Comparisons to life before COVID were commonplace: *“I hate not being able to do everything I used to be able to do. I hate that if I do too much, my body pays for it for days long to recover.”* Another person wrote, *“I felt so much more alive [pre-COVID] than I do now.”*

Future Outlook, Clinical Implications

Even amid this taxing condition, participants expressed hope for the future, both in terms of learning more about managing long COVID symptoms and for some return to life as it once was: *“My new normal is when everything works as before COVID, but different.”* Others recognized the challenges of living in the past, *“All I can really do is be hopeful to get back to some sort of ‘normal,’ or more likely I need to accept my new normal.”* Hope that things will get better remained. *“There are too many people trying to figure this out together and the strength of numbers will always make things happen quicker, but in the meantime, it will help everyone like me for the word to get out about the troubles of long COVID so [that] family members, friends, and employers can be sympathetic to the issues*

and work with the people so it is a little less stressful.” This sentiment was echoed by another who wrote, *“I hope we become more of a community of unity to be good to one another.”*

DISCUSSION

The aim of this manuscript was to highlight the stories of 5 patients with long COVID who are members of Henry Ford’s COVID Recovery Care PFAC. Aligned with the goals of this PFAC is the facilitation of collaborations between research and patient stakeholders to advance understanding of and care for individuals with long COVID. Through the collaborative and iterative process of sharing their stories, the patient stakeholders contributed by sharing their lived experience and further facilitated their connections with one another by reviewing one another’s stories.

While the sample size was small, these descriptions of long COVID symptomatology are similar to published research⁸ and also documented changes in cognitive functioning,⁹ quality of life, and mental health functioning.¹⁰ Moreover, the vast range of experiences and emotions are consistent with broader research conducted via social media across several years of the pandemic.¹¹ Changes in self-identity were recognized as part of long COVID in a recent systematic review.¹² Regarding clinical implications, an article in *The Lancet* identified a necessary first step toward addressing long COVID is for health professionals to listen, validate, and manage symptomatology among their patients with long COVID.¹³

There were limitations of this study design to recognize. Foremost, we did not employ strict qualitative methods, nor did we include a sufficient number of people from which saturation could be reached. Additionally, this work was conducted at a single health system, which limits generalizability.

In summary, this paper provides first-person perspectives of individuals living with long COVID and offers one avenue for providers to build understanding of first-hand lived experiences. It also showcases the opportunities of patient-engaged stakeholder groups, such as those supported by Henry Ford’s Patient-Engaged Research Center, to advance the care for individuals with long COVID. It is our hope that this work sheds light for those living with long-haul COVID-19 symptoms, for whom each day is one of learning and adapting. As described by one participant: *“Healing can be a very jagged line. The effects of long-haul COVID are real. ... I feel them. I experience them. I know that I am different.”*

Patient-Friendly Recap

- At a time in the pandemic when symptoms of the condition known as “long COVID” were emerging, five patients shared their lived experiences.
- Common long COVID symptoms included physical exhaustion, memory lapses, and difficulty breathing. Patients noted negative effects on their cognitive function, family relationships, and mental health, but also expressed hope for advances in treatment.
- Clinicians should gain an understanding of how long COVID impacts patients’ lives and be open to potential treatments developed as our knowledge of this novel disease evolves.

Author Contributions

Study design: Hecht, Murphy, Santarossa. Data acquisition or analysis: Hecht, Murphy, Santarossa. Manuscript drafting: Hecht, Adams, Dutkiewicz, Radloff, Wales, Whitmer. Critical revision: Hecht, Santarossa.

Conflicts of Interest

None.

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