

Short Communication

Clinical Programs for the Post-Acute Sequelae of COVID-19: What do they Offer?

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Abstract

As the acute COVID-19 pandemic continues world-wide, increasing numbers of survivors have presented to medical attention with what is now referred to as the “post-acute sequelae of SARS-Cov-2 (COVID-19) infection” or PASC. Clinics, programs and centers have arisen to provide care for these patients despite a lack of characterization of its epidemiology, symptoms and syndromes, risk factors, and course. This brief report describes the range of PASC recovery services and early observations regarding signs, symptoms and syndromes.

Keywords: Post-Acute Sequelae of COVID-19 (PASC); COVID-19 clinics; Post-acute COVID-19 clinics; COVID-19 recovery; Long COVID-19**Introduction**

As the COVID-19 pandemic continues to surge, increasing numbers of patients are returning months after their initial infection with residual symptoms, organ dysfunction, or new symptoms or syndromes presenting after an initial asymptomatic or mild infection [1]. These are now referred to as post-acute sequelae of SARS-Cov-2 (COVID-19) infection (PASC) but have been previously called post-acute COVID-19 syndromes, long COVID, or “longhaul syndrome”. PASC COVID-19 recovery programs have opened world-wide and across the United States (US). The purpose of this study is to examine the settings, descriptions and scope of PASC COVID-19 recovery programs (recovery programs), as well as the symptoms, signs and syndromes commonly encountered.

Materials and Methods

Recovery programs were identified *via*. 1) PubMed search including terms COVID-19, and long haulers, post-acute, post-COVID syndrome, persistent symptoms, long COVID, COVID clinics, COVID-19 recovery; 2) Internet search for COVID-19 program, clinic, practice, care, recovery; and 3) Review of all programs listed on patient-facing COVID-19 non-profit or social media websites [2-4].

Results

Ninety-three US recovery programs located across 31 states were identified. They have been dichotomized as independent (39%) or university-based in Table 1. Independent pulmonary programs (25%) rarely integrated other specialties, but may include or are closely

associated with pulmonary rehabilitation services. Rehabilitation programs (21, 58%) were highly represented, primarily offering ambulatory rehabilitation, although several offered telehealth services as well. Only two specific recovery programs were identified in sub acute care settings. Few independent rehabilitation programs offered and integrated other specialty services. Independent pulmonary and primary care programs often offered other specialty care *via*. referral rather than integration.

The majority of university-affiliated recovery programs are led by pulmonary medicine, often nested within existing pulmonary clinics (37%), 30% of which had been clinics focused on the care of patients with post-intensive care syndrome. Other university-affiliated recovery programs are set within rehabilitation programs (28%) or primary care clinics (18%). Referral-based interdisciplinary care, including pulmonary medicine most frequently, is offered by 32%. Most offer telehealth and in-person care; one program identified offers only telehealth.

Few programs describe their clinical model, assessment or scope of services; the majority offers a primary specialty consultative program, with some providing additional specialty services by referral. Few clinics offer multidisciplinary care in one site and as a part of a one assessment. Information about data collection, linkage to research studies, or outcome data is not available from the vast majority of PASC recovery programs. Our institutional hub-and-spoke model is comprised of a primary care-pulmonary-cardiology hub, with specific specialists, including behavioral health, neurology, rheumatology, dermatology, which are linked by a common electronic health record. This recovery clinic has more than 800 PASC patients, whose signs and symptoms coincide with those identified by patient-facing social media studies [2-4] and the literature [5,6].

Discussion

The limitations of this brief report reflect current limitations in obtaining detailed information regarding existing clinics without a published record as these services evolve. Currently post-acute sequelae of COVID-19 remain poorly characterized. Therapeutic trials have not been undertaken. Our experience suggests that these syndromes appear likely to require chronic disease management. Patients have reported persistent symptoms for almost a year following

Citation: Jacobs LG, Baniqued M. Clinical Programs for the Post-Acute Sequelae of COVID-19: What do they Offer? J Med Public Health. 2021;2(1):1011.**Copyright:** © 2021 Laurie G. Jacobs**Publisher Name:** Medtext Publications LLC**Manuscript compiled:** Mar 26th, 2021***Corresponding author:** Laurie G. Jacobs, Department of Internal Medicine, Hackensack University Medical Center, 30 Prospect Avenue, Hackensack, New Jersey 07601, USA; Tel: 1-551-996-3500; Fax: 1-551-996-3298; E-mail: Laurie.Jacobs@HMHN.org

Table 1: US COVID-19 Recovery Programs.

Primary Recovery Center Discipline	COVID-19 Recovery Program Model				All Programs, n (%)
	Independent		University-based		
	Primary specialty, n (%)	Additional Specialty Service(s) offered, n/n (%)	Primary Specialty, n (%)	Additional Specialty Service(s) offered, n/n (%)	
Rehabilitation	21(58)	0	16(28)	1/16(6)	37(40)
Pulmonary	9(25)	8/9(89)	21(37)	9/21(43)	30(32)
Primary care	6(17)	3/6(50)	12(21)	7/12 (58)	18(19)
Cardiology	0	0	2(4)	1/2(50)	2(2)
Behavioral health	0	0	2(4)	0	2(2)
Infectious Disease	0	0	2(4)	2/2(100)	2(2)
Neurology	0	0	1(2)	0	1(1)
Nephrology	0	0	1(2)	0	1(1)
Totals	36(100)	11/36(31)	57(100)	20/57(35)	93(100)

Note: All specialty specialties participating in a Recovery Center Program are identified in the table.

their original COVID-19 infection.

The breadth of symptoms and syndromes described by patients in our clinic, by social media studies and the literature, appear concordant but await prevalence studies. These symptoms require a comprehensive assessment with collaboration and care coordination across multiple professional providers, including primary care, pulmonary medicine, other medical specialists, nursing, social work, psychiatry, physical therapists, behavioral health, and others, either on-site or virtually. Recovery programs may well need to coordinate and manage care with outside agencies. It is essential that an expanded team share their diverse perspectives and interpretation of clinical data to characterize this new syndrome and meet patients' expectations for care. At present, many of these programs are grafted on existing rehabilitation and/or pulmonary clinics, are not scaled for the expected increase in volume that the surge of the last few months will produce, even though the disease epidemiology, timeline and course, remains undefined. Intake, assessment, data collection, and presumably, treatment modalities, vary. Although services may be linked by an electronic medical record, they may not be optimized to track patients, interventions, eligibility for clinical trials, and other data requirements, or be easily extracted.

It is also essential that these recovery programs offer patient support and behavioral health, rarely included in current programs reviewed herein. The prevalence of anxiety, depression, disability, and pain, is high among patients with PASC. Behavioral health and support for disability, whether short or long term, resulting from these symptoms, is essential.

Patients suffering from post-acute COVID-19 syndrome require the continuum of chronic care services. Recovery programs should be designed for the task. The opportunity for existing and emerging recovery programs to collaborate in the collection of data and biologic material for study of PASC's pathophysiology, genetic associations, biomarkers, the impact of vaccines, course, outcomes, is underway. This will require a common vocabulary with regard to observations and syndromes. It will also build the collaboration necessary to rapidly undertake clinical trials for treatment and prevention. Ultimately, in order to provide quality care, outcomes must also be defined and drive the design and delivery of PASC care.

Conclusion

Recovery programs to address post-acute sequelae of COVID-19 infection are proliferating. Many focus on one area of symptomatology rather than offering multidisciplinary comprehensive assessment required for the state of the science and clinical care to advance rapidly and serve the patients most effectively.

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