

Perspective

Long COVID and Health Inequities: The Role of Primary Care

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Policy Points:

- An estimated 700,000 people in the United States have “long COVID,” that is, symptoms of COVID-19 persisting beyond three weeks.
- COVID-19 and its long-term sequelae are strongly influenced by social determinants such as poverty and by structural inequalities such as racism and discrimination.
- Primary care providers are in a unique position to provide and coordinate care for vulnerable patients with long COVID.
- Policy measures should include strengthening primary care, optimizing data quality, and addressing the multiple nested domains of inequity.

THE PANDEMIC HAS HIGHLIGHTED AND EXACERBATED HEALTH inequities in both acute coronavirus disease 2019 (COVID-19) and its longer-term sequelae.^{1–4} Symptoms of COVID-19 persist in approximately one in 10 patients.⁵ Acute symptoms include shortness of breath, cough, myalgias, disturbances in the sense of taste and smell, fatigue, fever, chills, and, less commonly, rhinitis and gastrointestinal symptoms. By contrast, the term “long COVID,” coined by patients, refers to both postacute symptoms (lasting more than three weeks) and chronic symptoms (lasting more than 12 weeks).⁶ Long COVID is a multisystem disease of unknown cause whose manifestations, while partially overlapping the acute presentation,

vary widely among patients and are exacerbated by comorbidities and vulnerabilities (Box 1). It occurs in adults who were hospitalized and those who were not⁶⁻⁸ and (more rarely) in children.⁹ At the time of this writing, the United States had more than 17 million diagnosed cases of COVID-19,^{10,11} which translates into approximately 1,700,000 people with long COVID. This does not include the likely underreporting of COVID-19 cases, the proportion of which in one study ranged from one in three to one in 406.¹² The implications for health services are substantial. Given the heterogeneity in definitions of long COVID and the lack of centralized registries of patients with the disease, those who might suffer from long-term symptoms might mistakenly be recorded as recovered.

The natural history of long COVID appears to be gradual improvement over time in most cases, though recovery is typically measured in months.^{6,8} Some patients require comprehensive assessment to exclude serious complications that might underlie their symptoms (notably, thrombo-embolic disease of the lungs, heart, and brain), along with holistic clinical intervention and follow-up. Patients without concerning symptoms should be supported but spared overinvestigation and overmedicalization.^{6,16,17} Those who have survived admission to an intensive care unit and those with preexisting respiratory, cardiovascular, or cerebrovascular disease are likely to require more specialized and prolonged rehabilitation.^{16,18,19} Given the paucity of evidence, it is currently unclear which of these issues related to long COVID are directly related to or caused by the disease itself and which are unrelated but may be made more difficult to treat owing to COVID-19 and its after-effects.

Acute COVID-19 is associated with significant racial disparities.²⁰⁻²³ Black, Latinx, American Indian, Alaska Native, Asian, Native Hawaiian and Pacific Islander, and other non-white racial groups in the United States are less likely to have access to testing;^{24,25} more likely to be infected;²⁵⁻²⁸ more likely to be hospitalized overall,²⁹ though less likely to be hospitalized for any given level of severity,²¹ and more likely to have an adverse clinical outcome (including death).^{21,27,30,31} In addition, these racial groups are overrepresented in high-risk occupations, including those with a higher risk of mortality from COVID-19 (e.g., health and care workers, hospital porters and cleaners, bus drivers, transport workers),³² are less likely to have adequate health insurance,³³ and are less likely to receive compassionate end-of-life care.³⁴ They are also more likely to be severely affected economically with job losses or

Box 1. Some of the Many Manifestations of Long COVID^{6,13–15}

The Lived Experience

Symptoms may be continuous or fluctuating

- Fatigue
- Breathlessness
- Cough
- Nonspecific chest pains (“lung burn”)
- Palpitations or dizziness
- Neurocognitive difficulties (“brain fog”)
- Abdominal pains
- Muscle pains
- Hoarseness
- Skin lesions, especially chilblain-like on the extremities (“COVID toe”)
- Mood swings

Clinical Examination and Tests

May identify signs of past infection, active inflammatory disease or systemic complications, including

- Fever
- Positive antibody tests for COVID-19 (but absence of evidence of infection does not exclude long COVID)
- Abnormal blood panel (e.g., white cell count, C-reactive protein, brain natriuretic peptide, troponin, D-dimer)
- Thrombo-embolism (coronary, pulmonary, cerebral)
- Cardiac disease: myocarditis, pericarditis, dysrhythmias, heart failure
- Respiratory disease: pneumonitis, pleural effusion
- Neurological disease: stroke, seizures, encephalitis, cranial neuropathies
- Psychiatric conditions: posttraumatic stress disorder, depression, anxiety

Comorbidities and Other Relevant Concerns

Note: not all new symptoms in a patient after COVID-19 are due to long COVID

- Long-term conditions (e.g., diabetes, heart failure, hypertension, asthma, epilepsy)
 - New conditions unrelated to COVID-19 (e.g., infection, suspected neoplasm)
 - General health and well-being including sleep status, nutritional status, sarcopenia, tissue viability
 - Family circumstances (e.g., bereavement, unemployment, domestic conflict)
 - Community resilience (e.g., loss of community resources or leaders, lockdown-related restrictions)
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lack of access to welfare.^{35,36} While they are also more likely to have comorbidities and poor prognostic features (e.g., obesity),^{4,37} controlling for such factors reduces the differences in COVID-19 mortality among ethnic groups and, in some cases, eradicates them altogether,^{20,38} prompting calls to go beyond “biological” explanations.^{3,39} Later we discuss structural explanations for racial disparities in the onset and outcome of acute COVID-19, summarized schematically in Figure 1.^{2–4,20,40–42}

Whereas the association between race/ethnicity and health inequity in acute COVID-19 is now well established, the association of inequities with long COVID is relatively unexplored.^{4,22,43} To improve the care of vulnerable populations with long COVID, we need to (1) understand, acknowledge, and engage with the densely woven patterns of disadvantage that encumber those with postacute and chronic illness;⁴⁴ (2) strengthen existing services, especially in ambulatory primary care; (3) optimize data quality and use those data strategically for planning and monitoring; and (4) provide access to resources in acknowledgement of the multiple nested domains of inequity operating at global, national, community, and individual scales. We will consider these approaches in turn.

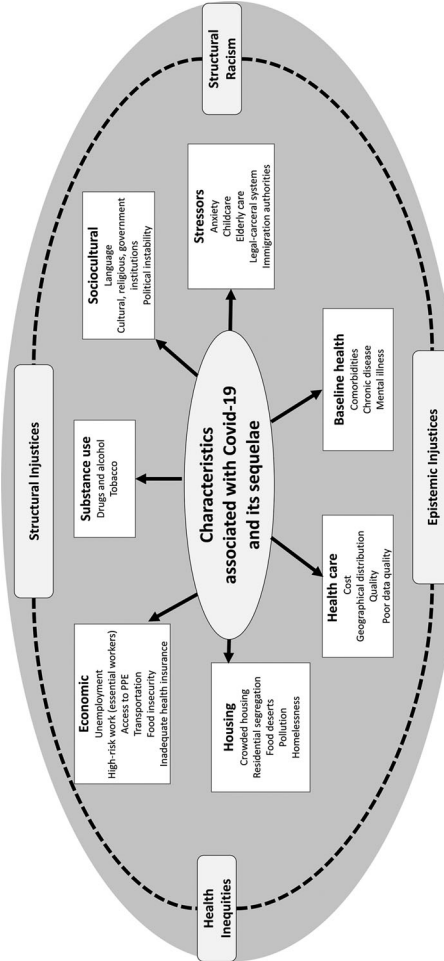
Understanding the Multiple Barriers to Health Equity in Long COVID

Vulnerable groups encounter a range of barriers to health care linked to such social determinants as gender, race/ethnicity, education, occupation, and transport.^{45,46} Next we consider those barriers that may be particularly relevant to long COVID.

Economic Barriers

Long COVID has a negative economic impact in at least two ways. The first is medical expenses.⁴⁷ A single acute COVID-19 case without hospitalization has a direct medical median cost of \$3,045: if health care is sought after infection (e.g., outpatient visits), then the cost increases to \$3,994.⁴⁸ In case of hospitalization, the median cost is \$14,366 and rises to \$18,579.⁴⁸ These figures are the direct cost to the payer. Out-of-pocket costs include multiple other domains not directly

Figure 1. Relationship Between Structural Inequalities and COVID-19, Which Explains the “Confounders” in the High Mortality Rates for Some Ethnic Groups



Adapted from an original diagram by Bentley² under Creative Commons License.

connected to medical services, since, like any multisystem illness, COVID-19 can affect many areas of life. Although postacute and chronic stage economic data are not available, we can infer that the follow-up and treatment of the multisystemic symptoms will vastly increase health care costs, particularly for some patients. For many patients, this cost would be a deterrent from screening or, for those without health insurance coverage, seeking advanced care.

Postacute care ranges from skilled nursing facilities to inpatient rehabilitation to home health agencies.¹⁴ In the United States, the cost of skilled nursing facilities is an average of \$6,844 per month for a semiprivate room to \$7,698 for a private room. A health care aide costs an average of \$20.50 per hour, a rate that may increase in the evenings, on weekends, and on public holidays.⁴⁹

Vulnerable populations facing postacute and chronic COVID-19 may have little or no health insurance coverage.^{47,50,51} Black and Latinx people tend to be uninsured at higher rates than white people are, particularly in states that did not expand Medicaid under the Affordable Care Act (ACA). As noted earlier, this affects the costs of testing and the resultant willingness to be tested. The Families First Coronavirus Response Act (FFCRA) requires “certain plans to cover specified COVID-19 testing services without cost sharing . . . however there is no federal requirement specifically mandating private health insurance coverage of items or services related to COVID-19 treatment.”⁵² The coverage of Medicaid and the Children’s Health Insurance Program (CHIP) testing and diagnostic services varies by state, and most out-of-pocket costs are capped at 5% of family income.⁵³ Even though Medicare beneficiaries do not pay the out-of-pocket cost of COVID-19 testing and telehealth is temporarily covered, they will pay deductibles, copays, or coinsurance in the case of hospitalization.⁵³ Uninsured individuals—around 28 million nonelderly people, many of whom have jobs with a high exposure to COVID-19—must pay the full cost.^{50,51}

The second economic barrier is that debilitating and disabling symptoms interfere with people’s ability to work and hence to generate income for themselves and their dependents. The vulnerable in society have less job security, less flexibility in their roles, and less entitlement to sick pay and occupational health services.⁵⁴

Geographical Barriers

People living in medically underserved areas, who include disproportionate numbers of Black and minority ethnic groups, may have inadequate access to primary care.^{55,56} Yet vulnerable groups also have more comorbidities and hence a greater need for care.⁵⁷ Poor public transportation may delay vulnerable groups' access to health care even in areas not formally designated as medically underserved.⁵⁸ The American Society of Civil Engineers recognizes that "despite increasing demand, the nation's transit systems have been chronically underfunded [and] many Americans still have inadequate access to public transit."⁵⁹ The COVID-19 pandemic exacerbated the underprovision of transport owing to safety concerns.^{60,61} This lack of reliable transportation is a barrier in accessing health care, even though the use of public transportation (more common among racial and ethnic minorities) is a known risk factor for COVID-19 infections.^{62,63}

Housing and Segregation

Vulnerable populations tend to live in high-density areas and crowded residences,⁶⁴ which are associated with an increased risk of COVID-19 infection. Residential segregation underlies and exacerbates health disparities.^{65,66} For example, worse outcomes in tuberculosis have been noted in communities where Black and Latinx individuals are predominant, reflecting such segregation,⁶⁷ and COVID-19 is expected to behave similarly.^{40,68}

Occupational Barriers

Vulnerable groups are disproportionately represented among essential workers (e.g., bus drivers, certified nursing assistants).⁶⁸ Such workers are often overlooked, undervalued, and stigmatized, and they are currently facing higher physical and mental health risks without the financial means to opt out of their work.^{54,69,70} In addition to being at a greater risk of acute COVID-19 by not having adequate personal protective equipment (PPE) and less ability to physically distance,^{54,71} essential workers now also face a disproportionate burden of long COVID.

Other occupational groups that are likely to have high levels of long COVID include those whose environmental conditions place them at a high risk of acute COVID-19. For example, employees at meat

processing plants work in close proximity with one another and in cold, wet and noisy environments, leading in some cases to “superspreader” events.⁷⁰ Symptomatic or exposed employees often are ineligible for the sick leave and health insurance that might allow them to remain at home.⁴⁹

Workers in these occupations typically lack the flexibility to deal with the protracted or relapsing-remitting nature of long COVID symptoms, together with the pandemic’s continuing implications (e.g., no child care when schools close).⁷² In some cases, these workers face a moral trade-off between protecting their own health and ensuring a basic family income.

The Case for Strengthening Primary Care Services

Barbara Starfield’s seminal research, published in this journal, showed that traditional primary care—first contact, holistic, person-focused, comprehensive, continuous and coordinated—saves lives, reduces suffering, and lowers overall health care costs.⁷³ A review in the *British Medical Journal* argued that these very characteristics, which enable continuity of care, a respectful therapeutic relationship, and support as patients pace themselves carefully toward recovery, make primary care an ideal setting for managing many (though not all) cases of long COVID.⁶

The effective management of long COVID requires, first and foremost, recognition of the condition and empathic validation of the patient’s experience. It also requires a skilled, generalist assessment of the multisystem disorder (which may affect virtually every organ in the body) and judicious referral to cardiology, respiratory, neurological, mental health, or other specialist colleagues as appropriate.⁶ A primary care clinician who knows the patient and his or her life circumstances is in an optimal position to coordinate and personalize the recovery plan and understand the barriers the patient faces while struggling to follow it. A comprehensive training program for generalist clinicians, along with care pathways, guidance, and criteria to which patients should be referred, must underpin a primary care-led long COVID response. A diversified health care workforce, greater cultural humility, and fewer health inequities are part and parcel of this effort, considering the role of racial injustice in long COVID.^{33,74}

Even before the COVID-19 pandemic, vulnerable populations in the United States faced inequitable access to primary ambulatory care and quality health insurance.^{55,75,76} Accordingly, health care providers should expect these challenges to be even greater with the burden of chronic disease related to COVID-19. Given the large numbers involved, primary care is likely to lack the capacity to provide ongoing, holistic, and equitable care to all who need it. The “COVIDization” of health services (i.e., a reorientation of clinicians and service models to deal with the pandemic’s immediate impact) has led to fewer emergency department visits for heart attack, stroke, and uncontrolled diabetes;⁷⁷ avoidance of routine medical care;⁷⁸ and (in European studies) delays in referrals for suspected cancer.^{79,80}

It is important to note that long COVID, particularly in vulnerable groups, may be complicated by long-term conditions, notably diabetes, hypertension, ischemic heart disease, and chronic mental health conditions.^{26,71,81} Hence, there is an argument for resourcing whole-patient primary care support rather than (or in addition to) providing ring-fenced funding solely for long COVID. The early stages of the COVID-19 pandemic highlighted issues with the resource allocation framework that discriminated against age, disability status, and racial/ethnic disparities.^{82,83} This raised the ethical question of how best, in a resource-limited setting, to allocate resources to support patients with long COVID without hurting those suffering from other chronic conditions, especially since both COVID-19 and noncommunicable diseases are clustered in minority groups. The World Health Organization’s ethical values for a fair process in allocating resources—transparency, inclusiveness, consistency, and accountability—may help guide difficult decisions in which resources are limited.⁸⁴ Also relevant are wider political-economic questions, including the democratization of systems that concentrate wealth and disempower the poor.

The Importance of High-Quality Data and a Learning Health System

The long-term prognosis of long COVID is unknown. Not only do we not know whether or how much a damaged myocardium, lung, or brain may recover, we also do not know to what extent the ethnic and racial

inequalities observed in acute COVID-19 will be mirrored—or even exacerbated—as the disease becomes chronic. Unless we systematically measure inequalities by race and ethnicity, they will remain invisible, and poor outcomes in some groups will be attributed to biology rather than to the structural determinants discussed earlier, such as poverty, overcrowding, geographical underprovision, barriers to access, and systemic racism more broadly.^{23,85}

The collection of comprehensive, public, transparent, patient-centered, and multidomain clinical and epidemiological data should be (but appears not to be) an urgent national priority in the United States. Indeed, the COVID Tracking Project claims that because of the lack of official source-providing data, it is collecting the most complete data available, including filing and partnering with Boston University's Center for Antiracist Research to track racial and ethnic data reported by states.⁸⁶

Primary health care could complement such initiatives by adopting the principles of learning health systems and integrating data collection, analysis, and actionability through clinical practice.^{87,88} Such an approach would require investment and coordination to ensure rigorous and consistent coding, data quality assurance, information governance, and effective and timely feedback into clinical practice.⁸⁹ As an editorial in the *Lancet* argued, “Detailed data on COVID-19 by age, sex, or ethnicity/race are scant but should be available routinely and automatically.”²⁰ In other words, a partnership between medicine and public health is warranted.

The collection of consistently coded data sets from individual patient's primary care records regarding postacute and chronic COVID-19 would help support much-needed research on this new condition.

Although some health care systems in the United States had begun to collect data on social determinants of health before the onset of the pandemic,^{90,91} collecting such data may or may not influence the inequities that affect communities. Primary care providers are in a unique position to link the collection of social determinant data with intersectoral action with governments and institutions to redistribute resources in a way that addresses these determinants and averts the inequitable impact of long COVID on patients and communities.

Addressing the Social Determinants of Health in the United States

The United States is notorious worldwide for its high-cost and profit-oriented health care system, which is also marked by striking inequalities.⁹² Millions of Americans are facing prohibitive medical expenses while being underinsured, uninsured, or unemployed.^{32,93} Furthermore, those who are—directly or indirectly—newly unemployed as a result of COVID-19 and its sequelae are often also newly uninsured.⁷⁶ As King commented recently, “The patchwork way we govern and pay for health care is unraveling in this time of crisis.”⁹⁴ It is time to demand reform.

Outside the United States, the goal of universal health care is widely accepted as a means of achieving social justice and reducing health care disparities, and a strong primary health care system is viewed as the cornerstone of such a system.^{95,96} Universal health care would address the current insurance coverage disparities faced by racial and ethnic minorities, who are more likely to face unemployment and underinsurance due to the pandemic.^{94,97} Despite the potential that universal health care—whether through a socialized single-payer system as in the United Kingdom, social insurance as in Germany, or a mixed public and private model as in the Netherlands⁹⁸—offers to mitigate economic and accessibility barriers to health care,⁹⁸ it is currently contested in the United States.⁹⁹

In the more immediate future, there is a strong argument for expanding Medicaid coverage for vulnerable people with long COVID, as was done for the acute phase of the pandemic.^{52,53,76} Medicaid allows low-income persons to access COVID-related care after being infected. Medicaid can also function as a safety net for those becoming unemployed and uninsured, but this would require public support and the political will to increase federal funding to states and to make policies more consistent in time of widespread job loss.¹⁰⁰ Such an approach would acknowledge that this disease (1) is a unique and devastating event not just for individuals but also for families and communities; (2) affects the vulnerable disproportionately; and (3) has long-term physical, social, and economic effects that could be partly mitigated by the provision of medical care and support. As professionals who are closely embedded in their local communities and who specialize in managing illness in a family and

social context, primary care clinicians should organize and advocate as a group for health equity in the vulnerable population who now suffer—and will suffer—from long COVID.

More broadly, primary care clinicians should take a collective stance against income inequality, racism, and discrimination. Being discriminated against and economically disadvantaged leads both directly and indirectly to physical and mental changes that increase a person's vulnerability to disease.¹⁰¹ Without tackling the root causes of inequity, neither COVID-19 itself nor its long-term effects can begin to be addressed.^{3,45,85}

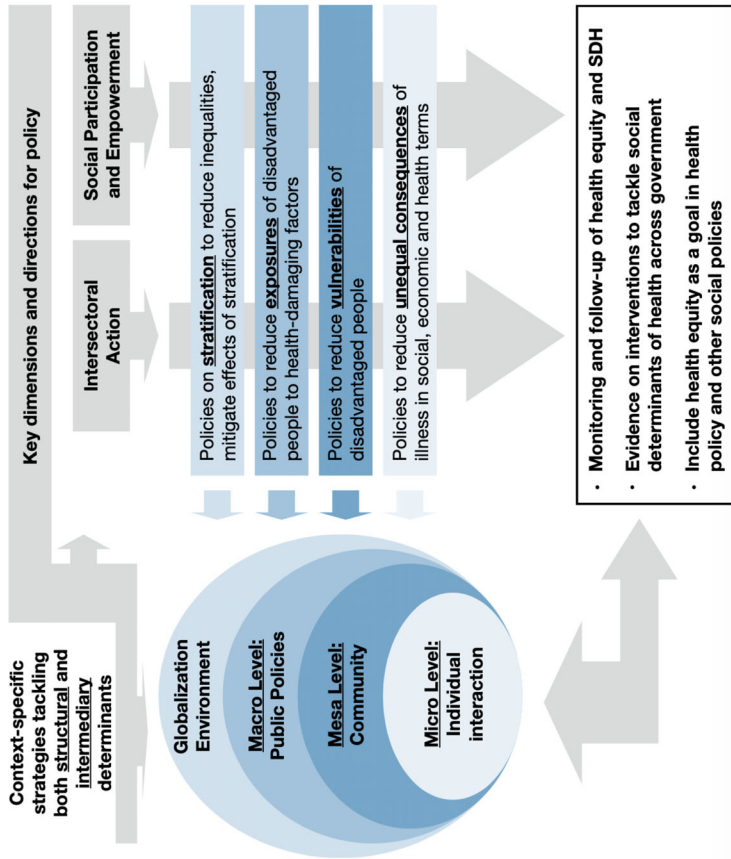
The Need for Multilevel, International Action on Social Determinants

A report from the World Health Organization in Health Organization in 2010 provides a useful framework for informing policy intervention to address the impacts of the pandemic (Figure 2).¹⁰² It recommends addressing multiple intersecting and nested domains in strategies oriented to reducing or mitigating the social determinants of health.

As explained earlier, government should address inequalities at both the individual and community levels that are linked to work, housing, and transportation, as well as education and food supply. Data from primary care providers in a learning health system can help inform and monitor specific policy interventions at these levels. But such data could also contribute more indirectly to advocacy and action for solutions at national and international levels.

The global, ecologic environment, for example, in addition to explaining the origins of the pandemic via animal-human spread, creates the inhumane and unsafe conditions in which many people, especially low-status essential workers, live and work. For another example, the recurrent “superspreader” outbreaks of COVID-19 in US meat-packing plants¹⁰³ cannot be fully addressed without considering the meat supply's business drivers and corporate culture. In recent years, this sector has seen extensive consolidation (small plants closing and being replaced by very large plants) and vertical integration (a single firm controlling the entire supply chain from the farm to the supermarket). These businesses are now typically owned by vast international companies employing thousands of workers to achieve economies of scale.¹⁰⁴

Figure 2. Framework for Multilevel Policy Intervention to Address Social Determinants of Health (reproduced from Solar and Irwin¹⁰²) [Color figure can be viewed at wileyonlinelibrary.com]



Corporate social responsibility has been limited, with a progressive erosion of workers' rights to sick leave and other benefits.¹⁰⁵ Since a high proportion of workers in the meat business are migrants, we also need to take account of international labor standards as well as domestic laws.¹⁰⁶

Conclusion

In the United States, COVID-19 is shifting from an acute national disaster to a chronic policy crisis, made no easier by the recent political context. The overall problem is bigger than any of us, individually or even collectively, can solve. There are, however, specific measures that we can take to reduce the impact of long COVID on vulnerable groups. First, primary care providers need to understand, recognize, and engage with both the clinical and the wider aspects of this new condition, involving a renewed, broader collaboration with public health. Second, health services must be strengthened to a level proportionate to the rapidly growing need, including extending capacity and developing new training programs, care pathways, and guidance for primary care clinicians. Third, high-quality data sets should be collaboratively and systematically collected and used in real time to improve system learning and bolster the public health response. Fourth, attention should be paid to providing access to resources to combat problems, such as equitable access to and distribution of health care, in global, national, community, and individual settings. Fifth, with a view to the longer term, professionals should advocate collectively for the health care reform that is long overdue in this country. Finally, advocacy and data from primary care should be used to contribute to collaborative efforts to address transnational grand challenges such as the links between corporate interests, worker exploitation, and COVID-19.

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