Disparities in Post-Intensive Care Syndrome During the COVID-19 Pandemic: Challenges and Solutions

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Systemic disparities place minority populations at the greatest risk of contracting and dying from Covid-19, and there is robust literature documenting how structural racism has adversely impacted the well-being of Black, Latinx, and Indigenous people. To date, the predominant focus has been on how disparities impact patients before and during hospitalization with Covid-19. However, disparities in the post-hospitalization period remain unaddressed. Specifically, patients recovering from Covid-19 are at risk for a host of physical, cognitive, and psychiatric sequelae of critical illness, collectively termed “post-intensive care syndrome (PICS).” In the present article, we review the literature on disparities in PICS, highlight the personal toll of Covid-19 on our patients, and suggest solutions to anticipated challenges. We outline a three-pronged approach involving (1) the prevention of critical illness, (2) the deployment of short-term post-hospitalization initiatives, and (3) the implementation of long-term post-hospitalization and community-based solutions.

Covid-19 and Vulnerable Populations

From the time of its emergence, the Covid-19 pandemic has unsettled countries globally with its staggering virulence, morbidity, and mortality. The early experiences from many hard-hit countries highlighted that vulnerable patient groups, such as the elderly, are at particular risk for worse outcomes when infected with SARS-CoV-2. In the United States, however, the pandemic also has devastated other historically vulnerable communities. In particular, the disease has been destructive in immigrant, Black, Latinx, homeless, and Native American communities and tribes.
Individuals in these communities have experienced the highest rates of infection, complications, and mortality from SARS-CoV-2.

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How is Covid-19 Affecting Vulnerable Populations?

Existing national data are astounding and portend a grim picture for health care disparities. Analysis of early Covid-19 data from major cities across the United States explored the relationship between poverty, race and ethnicity, and the incidence of Covid-19-related disease and death. The results are striking: as neighborhoods become less non-Hispanic White, the incidence of disease and death progressively increases. The same is true when exploring poverty: as neighborhoods become poorer, the incidence of disease and death progressively increases, independent of race. The virus also strikes individuals facing circumstances of low-income and housing instability; for example, the Boston-based Healthcare for the Homeless organization detected a 36% positivity rate for SARS-CoV-2 among its population. Furthermore, while the virus initially largely spared rural communities across the country, it has wreaked havoc in one historically marginalized rural community since the beginning of its spread: the Navajo territory in the Southwest United States. The Navajo Nation currently has more cases per capita than any state in the nation. In short, these data demonstrate that Covid-19 is disproportionately affecting marginalized populations in the form of greater rates of transmission and a larger burden of disease and death.

Why Inequities Are Happening: A Look at the Higher Rates of Infection

Numerous, deep-seated problems have led to the increased infection rates observed in marginalized communities. First, minority populations are disproportionately represented among essential worker categories across the nation, including the health care and service industries, both of which require high-risk face-to-face interaction with large groups of individuals. Second, access to Covid-19 testing remains limited, and, despite being 8 months into the pandemic, the United States is still not conducting the minimum number of tests daily to adequately curb the spread of SARS-CoV-2. In communities of color, access to testing is further limited by inadequate nearby testing facilities, a lack of vehicles necessary to utilize drive-through testing clinics, provider bias that may lead to missed or delayed diagnoses, and historical mistrust of medical institutions. Thus, asymptomatic people with SARS-CoV-2 or mildly symptomatic people with Covid-19 may remain undetected for longer in these communities. Last, when testing is performed, isolation and quarantine might not be feasible options for individuals living in multigenerational households.
or those with unstable housing situations. Without testing and subsequent isolation, these individuals become vectors for the spread of the virus.

Overcrowding in households underlies medical experiences in cities in which multiple members of many large families are admitted to the hospital concurrently. At Massachusetts General Hospital (MGH), we saw this phenomenon firsthand among some of our most vulnerable patients, as described below:

Mr. G was a previously healthy man in his 40s. He worked in environmental services at a local conference center, and that particular night he was sitting in his bed struggling to breathe. He was admitted for progressive shortness of breath two days after a confirmed diagnosis of Covid-19. He was in physical and emotional distress. In Spanish, he described how he had been living in a two-bedroom apartment in Chelsea, Massachusetts, with his wife and two young children after his diagnosis. He could not physically separate from them. With the lockdown, he, his wife, and his two children—the youngest with health issues requiring visiting nurse services—were all at home together in a small space. With the visiting nurse furloughed, he and his wife had to attend to their youngest child. Between paroxysms of cough, the man interjected “¿pero que vamos a hacer?” What are we going to do? His wife had called earlier in the night informing him that she was planning to come to the emergency department with the children—they were all exhibiting symptoms of Covid-19—and she was afraid if she got sick there would be no one to take care of them. A physician who spoke Spanish was able to review his chest x-ray with him, showed him the worsening inflammation in his lungs, and explained that he would need to have a tube placed in his trachea so that he could receive mechanical ventilation to protect his injured lungs. The physician called his wife, now a patient in that same hospital’s emergency department, and reviewed the plan. Between sobs she similarly interjected “¿pero que vamos a hacer?” That night, the man was intubated in the intensive care unit while his wife and children were all admitted to the hospital, all diagnosed with Covid-19.

In this case, the virus spread easily because of the living circumstances of the family. However, this anecdote sheds light on another barrier that exacerbates the number of infections in certain communities in which resources are scant: limited English proficiency (LEP) and the decreased access to care that patients with LEP face. This language barrier can inhibit access to relevant health information and can delay timely access to care.

**A Look at Higher Complication Rates and Severe Illness**

In addition to higher rates of infection, individuals from marginalized communities face worse outcomes after contracting SARS-CoV-2. Black, Latinx, and Indigenous people experience higher rates of heart disease, type-2 diabetes mellitus, obesity, and other conditions that are associated with severe illness. Low rates of insurance among low-income and minority patients also contribute to the increased rates of severe illness from SARS-CoV-2 in these groups, with uninsured or under-insured individuals often postponing or avoiding care because of cost concerns. Moreover, communities of color experience a number of structural challenges, including poverty, residential segregation, poor historical relationships with medical institutions, and stigma and racial bias by providers, all of which contribute to poorer health status and outcomes.
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For patients with LEP who make it to the hospital, the quality of care may be lower than that for their English-speaking peers. Such individuals are often cared for by providers who do not share their language or cultural roots. Numerous studies have demonstrated that language concordance is linked to higher quality of care, better outcomes, and increased patient satisfaction. When provider language concordance is not available and interpreter services are required, it has been shown that patients, providers, and interpreters prefer utilizing in-person or video-assisted interpreter services as compared with telephone services. Because of limited personal protective equipment (PPE) during this pandemic, many in-person services, including interpreter services, have been reduced in hospitals, and video-assisted platforms can be more difficult to use compared with telephone-based services. This challenge could affect the quality of care for our patients with LEP and further complicate feelings of isolation during their experience with Covid-19 in the hospital.

Critical Illness and Post-Intensive Care Unit Complications in Patients with Covid-19

The primary indications for intensive care unit (ICU) admission related to Covid-19 include severe lung injury with acute respiratory distress syndrome (ARDS), acute cardiac injury with shock, and thromboembolic complications. Lengthy hospitalizations with ICU admissions often require an equally extensive rehabilitation period. Challenges in the post-acute care period can include severe fatigue, weakness, joint stiffness, dysphagia, and impaired mobility and activities of daily living (ADLs). Furthermore, patients who require prolonged ventilation during their ICU stay are more likely to experience anxiety, depression, post-traumatic stress disorder (PTSD), and neurocognitive deficits, collectively known as post-intensive care syndrome (PICS), which can persist for months to years after discharge. ICU-acquired weakness, a major complication of long intensive care stays, is independently associated with both higher post-ICU mortality and lower functional status at 6 months. Patients with such medical issues often cannot be safely discharged to home. Instead, they require care at a long-term acute care facility for rehabilitation. For patients who are discharged to home, extensive follow-up through home hospital programs and rehabilitation services has been deemed essential.
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Disparities in the Post-ICU Period

Critical-care physicians across the nation can attest to the disparities that we are already seeing and will continue to see as we move recovering patients toward discharge. Consider the following anecdote from a patient who received care at MGH:

Mr. A was a man in his 50s who worked as a cab driver. He believed that he had been infected while transporting one of his clients and had subsequently developed fever, cough, pneumonia, and ultimately ARDS requiring mechanical ventilation. His course was complicated by a stroke, renal failure, and persistent respiratory failure necessitating a tracheostomy tube for prolonged mechanical ventilation. He will require a prolonged course of rehabilitation, but, due to insurance difficulties, he has limited long-term care options. Weeks after his initial decompensation, he is still hospitalized while awaiting a bed at a long-term care facility. His medical team worries that he will not receive the support, advocacy, and high-quality care necessary for him to appropriately recover from this devastating course.

Even before the pandemic, individuals in vulnerable categories experienced poorer access to post-hospitalization services, lower quality of care, and, in turn, worse rehabilitation outcomes. Patients receiving Medicaid, who are disproportionately Black and Latinx, are less likely to be transferred to long-term acute care facilities or skilled nursing facilities after hospitalizations that include an ICU stay. Instead, they are more likely to be discharged to home. Once home, Black patients are less likely than white patients to see an improvement in ADLs following critical illness. Black and Latinx patients who are discharged to skilled nursing facilities tend to go to poorer-performing facilities as reflected by a number of metrics, including, but not limited to, readmission rates and successful discharge into the community.

Fighting Health Care Disparities in the Covid-19 Post-Hospitalization Period

The post-acute care period for individuals in vulnerable groups is fraught with disparities and requires a thoughtful coordination of potential solutions. Here, we propose a multifaceted approach to addressing many of the anticipated problems. Our approach centers on (1) the prevention of critical illness, (2) the deployment of short-term post-hospitalization initiatives, and (3) the implementation of long-term policy and community-based solutions (Figure 1).
Prevention of Critical Illness

The first step in curbing disparities in the post-hospitalization period requires that we prevent the spread of SARS-CoV-2. The most important strategy is to implement widespread testing. Only 96 million tests had been done nationwide as of late September 2020, falling short of the recommended 1,304 tests daily per 100,000 people needed to suppress the pandemic. In the
United States, the pandemic is constantly creating new hotspots. The most effective way to quell the constant growth of the pandemic is by contact tracing infectious individuals and implementing quarantine measures in areas where hotspots arise. This step may prove especially effective in more rural communities. For instance, the White Mountain Apache Tribe in Arizona has a Covid-19 mortality rate of 1.1%, significantly lower than the entire state, in large part due to community collaboration and contact tracing. As screening infrastructure is built, tests should be prioritized for vulnerable communities with a higher risk of virus contraction and rapid transmission. The virus heeds neither physical bounds nor social structures. If it is allowed to fester in one place, it will inevitably spread indiscriminately elsewhere, further necessitating the need for lockdowns and stringent containment efforts.

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We also must address barriers to testing by setting up testing facilities within recognizable places with minimal police or military presence. This method of community-based testing has been implemented by MGH to increase Covid-19 testing in Boston’s most harshly impacted neighborhoods. In order to identify which communities were at highest need for testing and support, the MGH prevention taskforce first evaluated where admitted Covid-19 patients lived and focused the efforts on neighborhoods with the highest number of contributing cases. For the neighborhood of Hyde Park, which predominantly houses Black residents and had one of the highest infection rates in the city, tests were made available via a mobile testing clinic located on a refurbished bus, which was parked near one of the neighborhood’s recreational areas. In the nearby community of Mission Hill, where about half of the residents are people of color, testing kits were delivered door-to-door directly to families in need.

A second important way for hospital networks and public health systems to engage in the prevention of critical illness is by expanding physical isolation practices and providing marginalized communities with information and tools to decrease spread of the disease. The Covid-19 pandemic has placed great financial strain on numerous marginalized communities. Financially impacted households have had trouble purchasing detergents, soaps, and hand sanitizers, all of which have been widely touted by the health care and scientific community as the basis of hygienic measures against the virus. The MGH Equity and Community Health COVID Response Team identified these issues during the early stages of the pandemic and quickly moved to help reduce the risk facing financially burdened families. This was accomplished by delivering care kits—containing groceries, masks, and hand soaps—to many hotspot communities in Boston. We successfully delivered a high volume of kits to areas of need through this initiative, thereby promoting health and hygiene in the community.

Ultimately, the best way to prevent the spread of SARS-CoV-2, and the critical illness resulting from the virus, is to develop safe, effective vaccines that can be distributed widely. Unfortunately,
investigators leading randomized clinical trials and other studies have historically struggled to enroll representative samples of underrepresented minority patients in their studies; this has continued to be the case for trials pertaining to Covid-19, including ongoing vaccine trials.\textsuperscript{27,28} There are several reasons for the woefully small numbers of patients enrolled in clinical trials. An often-cited reason is the mistrust with which underrepresented communities view the medical community as a result of infamous ethical breaches involving minorities—from forced sterilization and medical experimentation on enslaved Black people to the Tuskegee syphilis study and the case of Henrietta Lacks.\textsuperscript{6,29,30} Nevertheless, medical mistrust is not the only explanation. In fact, data are mixed when it comes to showing differences between non-Hispanic White patients and underrepresented minority patients in terms of the willingness to participate in medical trials.\textsuperscript{29,31} It has been more consistently demonstrated, however, that minority and marginalized patients face barriers in accessing potentially life-saving clinical trials.\textsuperscript{29,31,32} In order to address these barriers, we should employ strategies that would facilitate the participation of underrepresented patients, such as using plain language when describing the trial, sharing culturally appropriate information, designating trial enrollment and study centers in conveniently located settings with vouchers for parking, and employing providers who have trusted relationships with patients in these communities.\textsuperscript{32} Another potential way to improve enrollment is by involving underrepresented research and clinical investigators, as well as patient advocacy groups, in the planning and roll-out of these clinical trials.\textsuperscript{28,30} It is of the utmost importance to enroll underrepresented patients in vaccine trials for SARS-CoV-2, as these individuals are at greatest risk for viral transmission. Therefore, they are uniquely positioned to demonstrate the efficacy of vaccines in development. Once an effective vaccine is developed, it is important that we equitably deploy vaccines into these communities to quell the continued devastation caused by this disease.

**Deployment of Short-Term Post-Hospitalization Initiatives**

The second critical step in addressing health care disparities in the post-hospitalization period is the development of short-term solutions tailored to the health needs of those convalescing from Covid-19.

A primary initiative related to this step is the establishment of multidisciplinary PICS clinics dedicated to caring for newly discharged Covid-19 patients. PICS clinics aim to identify the physical, cognitive, and psychiatric sequelae of critical illness and deploy a multidisciplinary team intervention to improve long-term outcomes. While a host of services are available for patients recovering from critical illness, such as visiting nurse services and home physical and/or occupational therapy, many patients do not have adequate insurance coverage for these services. One aim for these PICS clinics is to identify these at-risk patients and ensure that they are linked to appropriate physical, cognitive, and mental health follow-up services. In this way, post-ICU clinics represent a model of clinical care that is meant to reduce disparities in access in the post-hospitalization period.

A number of institutions with pre-existing PICS clinics have been able to readily adapt their infrastructure to care for the burgeoning population of Covid-19 survivors, while other institutions have established new programs. At MGH, members of the division of Pulmonary and Critical Care created one such clinic (the Coronavirus Recovery, or CORE, clinic) to care for the diverse
patient populations discharged from the hospital’s ICUs following acute treatment of Covid-19. The primary goal is to screen for the common consequences of critical illness among patients and their families and to link these patients to appropriate care. These multidisciplinary clinics allow for streamlined referral to appropriate clinicians as well as consultation with personnel from other disciplines (e.g., social work, psychiatry, neurology, nutrition, speech language pathology, and physical medicine and rehabilitation) according to a patient’s unique set of needs. Ideally, the clinics should be accessible to patients regardless of insurance coverage in order to eliminate disparities caused by financial status.

Another initiative is the integration of interpreter services throughout the care continuum. MGH spearheaded such an effort by partnering with both its in-person and video/phone interpreters to cover the needs of its providers and patients. Foreseeing a potential shortage in interpreter services for commonly spoken languages such as Spanish, the hospital created a multilingual registry of its supporting staff and formed the Spanish Language Care Group (SLCG), which comprises a team of native Spanish-speaking MGH physicians. Employees within the registry who were fluent in needed languages and worked in deprioritized areas were redeployed through the course of the pandemic to clinical areas where their language skills were needed. Providers from the SLCG assisted with daily rounds, family updates, and admissions and discharges. The advantage of this group was that its members could knowledgeably relay clinical information while understanding and being sensitive to cultural concerns. The group is available to patients in-person or virtually at all times. This model appeared to be successful early on and thus was shared with other Boston institutions to improve care delivery efforts.26

A third way to address disparities in the acute post-hospitalization period is to support isolation practices for newly discharged Covid-19 patients. Current guidelines require such patients to complete a 10-day period of self-isolation at a secluded location with a private bedroom and bathroom, and minimal contact with other people, to minimize risk of transmission. This necessary provision places a strain on many patients who, either because of poor functional status or living situations, are not able to isolate alone in their own private suite. Although discharge to skilled nursing facilities or rehabilitation hospitals might be an option for some patients with good insurance coverage, the rehabilitation services sector in many instances has not been able to meet the needs of the incessant influx of newly discharged Covid-19 patients.

It is imperative to create housing options for patients whose living situations make it difficult for them to quarantine or isolate. The city of Chelsea, Massachusetts, which has a large number of immigrant residents living in multigenerational housing, sought to address this issue with the Isolation Hotel Initiative. By creating a partnership with MGH, the neighboring city of Revere, and the hotel chain Quality Inn, the town administration reserved 145 rooms for recently discharged patients at the Quality Inn in Revere. The hotel was staffed by MGH personnel, including a medical director, nursing managers, social workers, and nurses. To be covered 24/7, the facility required about 50 full-time equivalents on the roster, so clinical staff were redeployed from other deprioritized clinical areas. The Isolation Hotel Initiative opened on April 16, 2020, and, during its two-month operation, hosted at least 80 residents per week. The facility allowed for stricter monitoring of residents in potentially critical conditions, and many calls to the emergency department were made from the facility. Notably, this facility was used both for the quarantine
of newly discharged MGH patients as well as for Covid-19-positive individuals who had yet to experience symptoms severe enough for hospitalization but were unable to isolate in their intergenerational housing. Similarly, in partnership with the Governor of Massachusetts and the Mayor of the city of Boston, Mass General Brigham (MGB) established Boston Hope, a 1,000-bed medical center for patients recovering from Covid-19 and homeless individuals infected with SARS-COV-2.²⁶

Implementation of Long-Term Policy and Community Work Solutions

In parallel with the implementation of preventive services and short-term solutions, long-term policy and community-based solutions are necessary to ensure that, once the bulk of the pandemic has passed, individuals suffering from disparities are not forgotten.

The first approach is the implementation of policy changes regarding reimbursement for post-acute care services and coverage eligibility. Take, for example, Massachusetts, the state with the highest insurance rate, in which an estimated 97.2% of the residents are insured.³³ The state offers a robust insurance system with relatively broad service coverage, even for citizens eligible for MassHealth (i.e., Medicaid). However, MassHealth Limited—the sole option for undocumented immigrants with constrained finances—only covers emergency hospital visits. Thus, these patients are ineligible for essential post-hospitalization services (e.g., visiting nurse services).³⁴ In states that have not expanded Medicaid coverage, vulnerable patients who had been critically ill will find themselves facing large financial burdens that will restrain them from accessing necessary care options after hospitalization. Furthermore, should some of the remaining provisions of the Patient Protection and Affordable Care Act (ACA) be deemed unconstitutional, it could further exacerbate the burden faced by families who are most vulnerable during this pandemic. It is true that the bipartisan approval of the Families First Coronavirus Response Act (FFCRA) and the Coronavirus Aid, Relief, and Economic Security (CARES) Act has made inroads to support the uninsured and underinsured in this country. Nevertheless, many of the provisions will only remain in place while the pandemic is still considered a public health emergency.³⁵ Finally, as previously discussed, we know that a number of patients with prolonged ICU stays will have long-term disability. Consequently, many families will lose essential sources of income and will require supplemental security income (SSI) payments. However, undocumented immigrants, who pay billions into social security annually, are ineligible for SSI.³⁶ These patients will be left without a source of income or access to follow-up care. Financial instability and limited options for post-hospitalization care for undocumented immigrants affected by Covid-19 may result in preventable readmissions to hospitals and health care organizations. From a policy standpoint, legislation should be passed that extends coverage for post-ICU care to include all patients who were hospitalized with Covid-19. Furthermore, safety nets should be established to assist undocumented immigrants who become disabled as a result of the pandemic.

The second approach is the creation of longitudinal community-oriented programs that can increase the trust between marginalized communities and health authorities. For instance, the Isolation Hotel Initiative only had an average occupancy of 80 of 145 available beds per week, and Boston Hope never came close to reaching its 1,000-bed capacity. These low occupancy rates likely can be attributed to a variety of possible reasons, which may include cultural issues, the
preference of patients to remain close to their loved ones while isolating, the fear of being reported to Immigration and Customs Enforcement because of their immigration status, or concerns about coverage and changing public charge policies. Several interventions can be used to help allay some of these fears, including implementing policies limiting documentation of immigration status in medical records and ensuring the confidentiality of such information, educating providers on how to care for immigrant patients in a sensitive and confidential way, providing legal services and support, and nurturing empowerment and engagement among immigrants.

The creation of longitudinal relationships is also necessary to address the historical mistrust that hinders disparity-addressing initiatives. These relationships are particularly beneficial during an emergency such as a pandemic. At the local level, health care organizations should ramp up their collaboration with existing community-based organizations such as faith-based organizations and human rights organizations. These collaborations can take the form of financial assistance, outreach, and continuous involvement of these groups on patient advisory boards. Community health workers also can serve as key bridges between the health care system and their surrounding communities. One study in Philadelphia demonstrated that, for patients randomized into a community health worker program, every dollar invested in the program garnered an average return of $2.47 to the average Medicaid payer within a fiscal year. These collaborations would foster positive, valuable, and sustainable community relationships that can be leveraged in urgent situations, creating trust and a rapid and concerted response to future public health emergencies and other local health crises.

**Limitations and Challenges**

Our proposed solutions have a number of anticipated limitations and challenges that must be considered. Currently, we only have process metrics for many of these initiatives, so it is hard for us to make a statement about whether these strategies improved outcomes for our patients and their communities. Forthcoming analyses should evaluate patient-level outcomes and cost-effectiveness to determine which initiatives should be prioritized and scaled during this pandemic and in future public health emergencies. The Isolation Hotel faced a number of challenges, including the need to train redeployed clinical staff in an unfamiliar system and a lack of staff continuity. For patients in isolation, this already-difficult experience was exacerbated by limited time outdoors, the absence of group interactions, and insufficient mental health resources. If a similar initiative is ever needed again, it will require improved staff training and continuity along with more robust mental health services and activities for patients. In the end, despite the potential benefits offered by initiatives such as the Isolation Hotel initiative and Boston Hope, health care disparities from Covid-19 continue to persist. This reality reinforces the need to address both the root causes of disparities and their manifestations at all points along the care continuum. Finally, it might be politically difficult to pass legislation that (1) extends coverage for post-ICU care to all patients who were hospitalized with Covid-19 and (2) establishes safety nets to assist undocumented immigrants. Although we recognize the political difficulty of passing such legislation, we believe that doing so will improve post-ICU recovery for patients who contracted SARS-COV-2 and will help to mitigate the potentially costly downstream outcomes of this disease to public payers.
The Crisis That Comes Next

The Covid-19 pandemic has at once rattled the nation’s economy, health care system, and conscience, laying bare the long-standing disparities that have existed in our society. Unfortunately, the pandemic continues, and the full scope of the repercussions from this crisis have yet to be realized. As health care professionals and leaders in academic medicine, it is imperative that we address the disparities in care that exist along the Covid-19 care continuum—from prevention of illness to early identification and treatment of PICS. If we do not aggressively pursue measures to mitigate the growing disparities that we are witnessing, we may find ourselves with an irreparable health care crisis. Although work remains to be done, at MGB, in collaboration with local leaders and through community partnerships, we developed a number of promising initiatives to assist in preventing the next foreseeable crisis.

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