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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Autonomy of Persons Experiencing Homelessness Be Balanced With Public Health During a Pandemic?

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Abstract

The COVID-19 pandemic underscores long-standing challenges to the health of persons experiencing homelessness. This case commentary considers primary care clinicians' response to a patient who declines COVID-19 testing and isolation. This article also considers other outbreaks in the United States in which the autonomy of persons with low income or persons of color was neglected and calls for community engagement, policies that center interests of marginalized groups, and economic relief, including supportive housing.

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Case

Ms L is a 48-year-old woman with currently uncontrolled type 2 diabetes mellitus and a history of anxiety and depression. In March 2020, she presents with a persistent cough, shortness of breath, fatigue, and myalgia to a Health Care for the Homeless Program site. She reveals during an initial screening that she's been self-medicating with acetaminophen and alcohol.

Ms L declines testing for COVID-19 and for hotel-based non-congregate (isolated) housing funded through a Federal Emergency Management Agency program. Clinic staff members express concern to Ms L about her health and about her capacity to infect others. Despite education by staff about the importance of isolation and testing, Ms L states that she will return to her usual dwellings—sometimes in public transportation stations or vehicles, sometimes in an encampment, or sometimes in a women's congregate shelter, which has units for individual sleeping quarters and includes kitchens and other shared spaces.

When Ms L leaves the clinic, concerned clinic staff members confer with a member of Health Care for the Homeless legal counsel to see whether there is something else they can or should do to protect Ms L and others in the community. The attorney warns that

they should not attempt to alert shelters, public transit authorities, or police and emphasizes that Ms L has a right to make personal decisions with which others might disagree, since Ms L has decision-making capacity. Members of the staff feel discouraged after hearing this advice and still feel that, as clinicians, they have a duty to try to help protect members of the public. They wonder what to do.

Commentary

As clinicians with the Health Care for the Homeless Program, we commit daily to the ethical principle attributed to the Hippocratic Oath, *primum non nocere* (“first, do no harm”). However, we frequently find that patient-centered health care for people who lack housing presents a series of imperfect, insufficient choices. The COVID-19 pandemic made these choices common and complex. In this commentary, we shed light on how this case can be approached by examining (1) the care model and ethical framework of the Health Care for the Homeless Program, (2) historical precedent of fear-driven responses to prior US outbreaks involving people experiencing homelessness, and (3) ethical frameworks that offer insights into how clinicians can approach similar circumstances.

Health Care for the Homeless

The Health Care for the Homeless Program is ethically grounded in person-centered care, respect for autonomy, and respect for resilience. Person-centered care, as defined by the Institute of Medicine, entails “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹ Respect for a person’s autonomy means ensuring that the person is free from controlling interference from others and free from limitations, such as lack of understanding, that might prevent their making an informed decision or meaningful choice.² And respect for resilience presumes the strength and capacity of persons with whom we work and requires a **trauma-informed understanding** of their behavior and events in their lives.³

We also strive to “meet people where they’re at.” Every day we see patients juggling impossible circumstances who manage to care for each other and their own health and well-being. They do all this while living without their fundamental right to housing being met. Developing trusting relationships with persons we serve can guide us in supporting them as they overcome extremely challenging situations. Connections among Health Care for the Homeless Program sites and county and national public health agencies enable us to mobilize resources and to respond with care to our patients’ needs.

The COVID-19 pandemic has prompted redesign of typical walk-in models of care, in which persons seeking care enter the lobbies of shelters and drop-in centers. We now screen patients (eg, for COVID-19) by phone and provide many social and behavioral health services by telephone or video. We also expanded our street outreach team, ensure rapid access to COVID-19 test results, and have isolation and quarantine teams to provide comprehensive health care to people experiencing homelessness who have been exposed to or tested positive for COVID-19.

Yet, despite our training, experience, and resources, we still struggle to navigate how best to express respect for patients’ autonomy while minimizing harm to public health.² We’ve had little guidance from local or national leaders on managing this tension. In fact, we’ve seen extreme **politicization** of recommended safety measures, which has resulted in a dearth of guidelines we can use to respond to patients like Ms L.

Fear-Driven Public Health Responses

Evidence suggests that measures to protect the public from COVID-19 discriminate on the basis of socioeconomic status, race and ethnicity, and language.⁴ Protective behaviors, such as social distancing and working from home, are privileges less available to workers with low-income.^{5,6} Congregate settings for the poor, such as homeless shelters, have led to rampant spread of the virus.⁷ And contact tracing across the United States is complicated by lower access to COVID testing in many low-income neighborhoods, especially among those that have faced long histories of inaccessible health care.⁸ As a result, COVID-19 infections and related deaths have disproportionately affected Black and Indigenous people and other people of color with low income in the United States. In July 2020, risk of death from COVID-19 was 9 times higher for people living in poorer “substantially non-White” counties than in poorer “substantially White” counties.⁹ Disproportionately higher COVID-19 mortality rates among racial and ethnic minorities become even more striking when age-standardized for premature mortality. Non-Hispanic Black and Hispanic people lost nearly 7 times as many years of life—and American Indian/Alaska Natives nearly 9 times as many years of life—before age 65 as non-Hispanic White people between February 1, 2020 and July 22, 2020.¹⁰ Furthermore, the economic impacts of COVID-19 threaten to worsen centuries-long **patterns of structural racism** in the US housing market, with people of color disproportionately at risk for displacement from rental units.¹¹

Historically, public health responses to disease outbreaks in the United States have discriminated against the “other” based on xenophobia and classism.⁴ From smallpox to tuberculosis to HIV, disease containment policies have often focused on the poor and historically marginalized groups, worsening inequities in the name of the public good.¹² Tuberculosis provides the most relevant recent example of a disease that specifically affected the homeless community. In the 1990s, New York City mandated directly observed medication therapy, physical examinations, and detention of people to prevent disease spread or to enforce treatment.¹³ While such coercive measures were used on less than 4% of the more than 8000 patients with tuberculosis at that time, the regulations affected 17% of patients experiencing homelessness, 10% to 29% of patients using various types of drugs or alcohol, and 38% of patients with a history of incarceration.¹³ Similar orders in California in the 1990s used civil detention and arrest to treat tuberculosis in 1.3% of presenting cases and had a similarly disproportionate impact on marginalized populations.¹⁴ Furthermore, even with such draconian efforts, only 84% of detained persons completed treatment, and only 41% completed treatment within 12 months.¹⁴ Oscherwitz et al suggested that greater availability of housing and psychosocial services would result in less need for dependence on punitive approaches.¹⁴ Unfortunately, such suggestions led to little change.

Similar to other public health crises in our country’s history, the COVID-19 pandemic has focused attention on and pouring money into projects other than those that strengthen our society and address long-standing inequity. All the while, people living in poverty, who include disproportionate numbers of Black, Indigenous, and other people of color, continue dying at staggeringly disproportionate rates, leaving behind families who lack the support for housing, food, and basic income they need to survive.

Bioethical Frameworks

Bioethical principles and international law could offer clinicians guidance on how to navigate this complex confluence of challenging circumstances. Such guidance could detail how to balance the rights of individuals against those of the public and how to

support public good. The Siracusa Principles, developed by the International Covenant on Civil and Political Rights in 1985, contain explicit criteria concerning when and how to override rights of individuals for the health of the public. Such guidance emphasizes that limitation of rights cannot “involve discrimination solely on the ground of race, colour, sex, language, religion or social origin.”¹⁵ Given the social origin of homelessness, this guidance suggests that it would be inappropriate to impose any limitations on the rights of Ms L solely due to the circumstance of her being homeless. Yet broad interpretation of these principles leaves little latitude for protection of the health of the public.

Bioethics scholars Matose and Lanphier suggest that the “harm principle” be the basis of limitations of rights during the COVID-19 pandemic. They propose a “stringent requirement to prioritize the prevention of harm to others”¹⁶ with regard to both disease transmission (eg, social distancing and masking) and unintended harms of social restrictions (eg, lost employment, food insecurity, and violence for those sheltering in abusive homes). Preventing harm from disease transmission might suggest that Ms L be required to use available hotel relocation options. However, this requirement would infringe on Ms L’s autonomy and eliminate her agency in the decision about how to keep herself safe. Prevention of harm could also support provision of supportive housing (rather than compelled housing) as a fundamental human right required for Ms L’s overall health and well-being related to both COVID-19 and her other medical and behavioral health conditions.

Given the current vacuum of US leadership, with public health officials increasingly quitting their jobs due to threats of harm from their fellow community members,¹⁷ health care clinicians and local public health officials are left to navigate these challenges on their own. So, those of us who work for the Health Care for the Homeless Program will do as we’ve been trained to do: we’ll maintain our ethical framework of *primum non nocere* and person-centered care, respect for autonomy, and respect for resilience and build relationships with those we serve. Such relationship building—rooted in establishing trust, harm reduction, and trauma-informed care—aligns with expert opinion about dealing with difficult cases of COVID-19 among people experiencing homelessness.¹⁸ We also know it’s currently our only hope. By respecting Ms L’s autonomy, maybe over time she’ll trust us enough to partner with us to look after her own health and decrease the risks she poses to herself and to her broader community.

Conclusion

Because clinical care alone is insufficient during these difficult times, we call for leadership to develop policies that “center at the margins”—that is, policies that are designed with authentic input from people experiencing homelessness and other forms of oppression and marginalization.¹⁹ We believe such approaches could result in community-driven solutions that promote equity and overcome historic discrimination. They would focus on acceptable housing solutions, such as long-term permanent supportive housing. Such long-term solutions offer options that promise to overcome some of the tension inherent in this case between Ms L’s autonomy and her best interests and avoid the need to compel at-risk people to shelter in hotels and other temporary settings during a pandemic. Forward-thinking, long-term solutions like permanent supportive housing might allow us to emerge from this time of crisis stronger and with more humane policies.

Until that leadership arrives and policies are made to control this pandemic and others that may come after it, we will remain at work on the margins. We will work to build trust

and rapport with people like Ms L who most often have very important and relevant reasons not to trust clinicians and whose autonomy is often deeply tied to their strength and resilience. We know such approaches offer us the best hope of avoiding harm to patients or to the public while also respecting patient autonomy until society finds the will to ensure that all people have access to affordable, supportive housing.

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Editor's Note

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