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NOTES FROM THE FIELD

COVID-19 Pandemic Disrupts HIV Continuum of Care and Prevention: Implications for Research and Practice Concerning Community-Based Organizations and Frontline Providers

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More quickly and more vividly than they could have anticipated, people living with (PLWH) and those at-risk for HIV felt the impact of the COVID-19 pandemic, as they were asked to shelter in place and distance themselves from others. Over the months of March and April 2020, around the time shelter-in-place orders accelerated, community-based organizations (CBOs) have closed, medical offices have cut hours, and medical personnel have shifted from primary care to COVID-19 hospital units. We assess the extent to which the COVID-19 pandemic has disrupted the HIV Continuum of Care and Prevention—that is, testing, pre-exposure prophylaxis (PrEP), and primary care—and propose a course of action so that we may end the HIV epidemic in this decade.

Ending the HIV Epidemic Within this Decade

The United States Department of Health and Human Services has proposed a reduction in the number of HIV infections in the United States by 90% within the current decade [1]. The World Health Organization's 90/90/90 goal also aims to contain the HIV pandemic by 2030, at which time 90% of all people living with HIV (PLWH) are projected to know their HIV status; 90% with diagnosed HIV infection are projected to receive antiretroviral therapy; and 90% of those receiving antiretroviral therapy are projected to show viral suppression. Ending the HIV pandemic requires that we gather local knowledge on which to base sustainable action. It requires leveraging local efforts led by community-based organizations helping those at high risk for HIV navigate complex diffusion systems and promote health equity—a national priority to improve health access for all, regardless of geographic boundaries, race/ethnicity, and sexual orientation [2, 3].

Community-based organizations (CBOs) employ frontline service providers—social workers, health educators, navigators—to help (1) individuals of unknown HIV status access testing; (2) those at high-risk for HIV but who test negative to access physicians who can prescribe PrEP; (3) those who test positive for HIV to access primary care [4]; and all at-risk clients to access support services to help them stay on the HIV Continuum of Care and Prevention ("care continuum") [5–8]. Nonetheless, community-engaged research suggests that, prior to the COVID-19 pandemic, these frontline providers had not been consistent in *how often* or in *how* they linked clients to care continuum services. Using cross-sectional data from nearly 300 frontline providers in New York City, an epicenter of both the HIV and COVID-19 pandemics, our research shows that, in the six months prior to data collection, 50% of provider participants had linked fewer than five clients to HIV testing; 48% linked fewer than five clients to primary care; and 48% had not provided any client with PrEP education [9]. These numbers are worrisome, but longitudinal data show a brighter picture. We detected increased involvement in at least some service linkage from 76% providers at baseline to 81% over two years [10]. Nearly half (47%) of providers offered PrEP education at both of these time points; 19% started offering PrEP education since baseline; while 5% stopped offering education at follow-up [11]. Furthermore, evidence suggests that frontline providers who more frequently link clients to HIV services tend to do so as part of face-to-face client meetings, at which the provider might ask the client, while still in their presence, to contact the referral, or the provider might make the contact and hand the client written information [12]. This level of proximity is a challenge under the shelter-in-place and physical distancing orders.

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COVID-19 is Likely to Impede Ending the HIV Epidemic

Before we crafted this *Note from the Field*, our CBO partners (i.e. managers and providers) informed us that the COVID-19 pandemic had already disrupted all care continuum services. Physical distancing between providers and clients will likely have a negative impact on how often and how frontline providers will link clients to services. This opens up a field of inquiry needed to develop best practices for referral-making. The COVID-19 pandemic quickly exposed medical (e.g. difficult access to services, lack of testing and insurance), and structural (e.g. unemployment, food insecurity, geographic isolation) vulnerabilities which have also historically undermined individual- and system-level HIV prevention [13]. CBOs are following stay-in-shelter orders and using online platforms and telephones to communicate with clients. Some of these platforms are unreliable, and clients and providers alike may encounter difficulties navigating them; many do not have access to high-speed Internet or have enough of a data allowance on their cellular phone plans.

To offer basic information about HIV prevention, CBOs are turning to social media: teaching clients about HIV testing and PrEP; reminding clients of the importance of physical distancing; and providing social support for newly diagnosed individuals. Since access to in-person HIV tests has been hampered, one CBO partner mentioned about their network, "as far as I know, no one is doing any HIV testing right now." Another CBO offers at-home HIV test kits to high-need clients, but the number of kits available is limited. Frontline providers (e.g., PrEP navigators) are not allowed (confidential HIPAA compliant) to take client information from their offices, thus they have stopped making referrals to physicians who can prescribe PrEP. Providers have cut back on or stopped altogether making referrals to primary care. They are nonetheless providing limited harm reduction and support services, with all parties adhering to physical distancing—for example, clean syringes passed through mobile unit windows and food and other items dropped off in front of clients' homes. Meanwhile, CBO managers are working on safety protocols and are purchasing protective materials in preparation for resuming face-to-face consultation when the stay-in-shelter order is lifted.

Implications for Practice and Research

The COVID-19 pandemic presents multifaceted challenges to HIV service CBOs, including but not limited to resource shortages, low staff morale, and disruption to patient-centered service provision. Suspending services creates budgetary shortfalls for CBOs that heavily rely on program revenues [14]. Given the skyrocketing numbers of unemployment claims in the last two weeks of March and two first weeks of April [15], many vulnerable clients may not be able to make co-payments for services, even after CBO doors are open again. CBOs expect significant declines in private donations, as also observed in the 2008 recession [16]. Now and during the stay-in-shelter period, CBOs are likely to rely on small business and individual donations and government programs. They are likely to strengthen relationships with private and public partners (e.g., other CBOs) in their communities in order to advocate for more effective government responses such as those initiated in response to the Great Depression of the 1930s [17]. The pandemic has created a substantial decline in provider morale. Many have and will continue to lose colleagues and clients to COVID-19. With limited resources and capacities, they are likely to be forced to make difficult choices as to which cases to prioritize for services [18, 19]. CBO staff will likely face layoffs and/or reduced paychecks as organizations struggle to stay open. These factors will continue to impact negatively frontline providers' sprit, motivation, and mental health. Providers having day-to-day interactions with clients in primary care, outpatient, and prevention settings are poised to help PLWH and vulnerable individuals overcome HIV-related stigma, PrEP stigma, inadequate health insurance, and can help improve HIV testing rates [20–25]. Provider engagement of clients in referral-making processes seems to improve client access to HIV testing, PrEP, and primary care, even when provider caseloads are high, clients may lack insurance, and CBOs may fear losing clients and revenue to other CBOs [5, 26, 27]. However, in the face of COVID-19, such engaged, face-to-face interactions and referrals might not be feasible.

Community-focused research can help track the degree to which COVID-19 is disrupting CBO operations, provider behaviors, and client experiences and outcomes. The disruptions caused by COVID-19 allow us to see how the HIV care continuum has been undermined routinely by insufficient concrete and human organizational resources, and by failures to follow up and track provider referrals to HIV services. To demonstrate how structural failures, highlighted by the COVID-19 pandemic, prevent providers from keeping their clients on the care continuum, we must study how CBOs' organizational supports incorporate client perspectives. COVID-19 exposed the need for research to understand how high volumes of incomplete referrals—i.e. clients not accessing services to which they are referred—waste time allotted for services, increases costs, lengthen waitlists, and jeopardize health outcomes (e.g., retention in care, viral suppression) [6, 28]. Providers' active referral-making (including

subsequent coordination and tracking efforts) can facilitate clients' timely access to needed services and reduce waste of organizational resources (e.g., staff hours, social capital) [29]. Despite the growing emphasis on person-centered care [30–33], few empirical studies have investigated the implications of person-centered care for organizations offering HIV services [34–36]. We also need to look at current literature and identify not only gaps but the limitations of past research (e.g. lack of large-scale qualitative evidence and limited involvement of clients and providers). Doing so should help researchers address the limited evidence on referral-making and linkage practices that could help clients access the HIV services to which they are referred ("referral completion"), and, ultimately, end the HIV pandemic within this decade.

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