Mitigating Isolation of People Aging With HIV During the COVID-19 Pandemic

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Before COVID-19, the HIV/AIDS pandemic had arguably been the worst public health crisis in the United States. Although an HIV diagnosis was previously regarded as a death sentence, the development of combination therapy in the 1990s transformed HIV into a largely manageable chronic condition. The average US life expectancy after HIV diagnosis is 29 years, with some people living more than 50 years. By the end of 2020, an estimated 70% of people living with HIV (PLWH) were aged >50, and an increasing number of PLWH were aged >65. With age comes comorbid conditions. To date, the cumulative effects of living with HIV exacerbate age-related health vulnerabilities. How such effects can be mitigated is understudied and poorly understood.

Advances in effective treatments since the 1990s have produced the first cohort to age with HIV. As such, we are only beginning to learn about their mental, physical, and psychosocial needs and how to deliver effective treatment and services to address their unique health challenges. These challenges are compounded by past and current health discrimination experienced by populations aging with HIV, including sexual minority groups and economically and racially disenfranchised people. Many in these populations have also endured substantial traumatic losses from AIDS in their chosen families, loved ones, and social supports, contributing to high rates of depression and isolation in more than half of older adults with HIV. People with untreated HIV and depression double their risk of mortality, further pointing to the need for integrated care.

The health disparities (eg, high rates of non–AIDS-related cancer, heart disease, depression) including immune deficiency experienced by people aging with HIV before the COVID-19 pandemic make them especially at risk not only for increased adverse outcomes from the virus itself but for the psychological and social challenges it presents. Beginning in March 2020, the COVID-19 pandemic prompted shelter-in-place orders nationally. Although the stay-at-home order was a necessary strategy, it further increased the isolation and social distancing faced by people aging with HIV and created barriers and unintended hardships in accessing medications, health services, and other resources.

For many long-term HIV survivors, the COVID-19 pandemic parallels the early AIDS epidemic, which was characterized by delays in acknowledging and addressing the pandemic and delayed safer sex guidance. These circumstances may trigger feelings of loss and anxiety, which parallel posttraumatic stress disorder resulting from AIDS Survivor Syndrome, defined by Tez Anderson as “the spectrum of sustained trauma survivorship resulting from living through the AIDS pandemic.”

But what is the solution to ensure people aging with HIV are physically and mentally healthy, not only during the COVID-19 pandemic but also after the pandemic is over? How do we reach people aging with HIV who may be socially and physically isolated and who are being further marginalized by multiple pandemics? One possible solution to address the increasing prevalence of depression and isolation caused by limited mobility and stay-at-home orders is to facilitate social connections for people aging with HIV in the form of a virtual village.

Virtual villages are meant to help older adults avoid isolation, stay connected with their community, and access services, allowing them to age in place for as long as possible. Dozens of virtual villages exist across the country, but most
serve high-income people aging with HIV in major cities. A statewide example is the Village Movement California. However, a village and a virtual village are different from each other in that a virtual village primarily connects people using the internet. During the COVID-19 pandemic, virtually connecting may be the only option when physical distancing is encouraged or mandated. One argument against pushing for more virtual connections among older adults is that they may lack the requisite skills in technology, especially emerging technology, or have inadequate internet access, reflected in their unreadiness for telemedicine. Still, research from the Pew Research Center from May 2020 shows that 42% of adults aged >65 in the United States have smartphones and 67% have internet access. New technology may be useful: computer tablets such as iPads allow for increasing text size and have been shown to be effective visual aids. Lower-income adults aged >65 may have less internet access than their younger counterparts, but examples on how to bridge this gap are emerging, including an internet master plan in New York City.

A virtual village would not only connect long-term HIV survivors with each other and medical providers during times of isolation, but by drawing on new big data technologies, it can also connect various support systems. A virtual village is more than a resource; it can be a platform for centralizing communication across all parties, allowing people aging with HIV to quickly connect with medical and social service providers and systems to meet their health needs, while providing continuously updated information to evaluate and improve the quality and continuity of care. It can also facilitate activities, such as seminars and virtual fireside chats, for the exchange of knowledge and flow of new information for people to remain healthy.

The COVID-19 pandemic is unlikely to end all at once, and the population of people aging with HIV, who have an increased risk of both infection and mortality from COVID-19, may well need to stay physically isolated long after their surrounding community returns to normal life, particularly with their increased adverse outcomes from the disease and initial exclusion from vaccine trials. For example, additional caution will be required to protect the health of older adults with HIV until effective and easily accessible treatments are available or until an effective vaccine is developed. The virtual community can provide a continuous support network to mitigate social isolation, provide information on how people can continue to receive vital HIV medications, and identify when an older person is experiencing a health or mental health crisis that requires in-person engagement. When in-person resources are limited, the virtual village uses supportive artificial intelligence or automated bots to navigate or deliver psychosocial services. To be sure, the establishment of a virtual community will not be successful if it does not adequately address the financial and technological limitations experienced by people with a chronic disease, a modest familiarity with how to use social media, and a lack of financial resources to afford the online resources required to effectively use the virtual community. Thus, in addition to social capital, the success of the virtual village will need to draw on public and nonprofit resources to ensure it benefits the people most in need. People aging with HIV and key partners, caregivers, health care providers, and community advisory boards must be involved in each step of developing the virtual village so that we no longer need to ask, “If we build it, will they come?” Instead, we will ask, “If they build it, will they use it?”

We live in a hyper-mobile global community. As a result, COVID-19 will not be the last pandemic to threaten the health of people around the world, particularly those most vulnerable to new infection and outcomes from infection. Although the COVID-19 pandemic illustrates why such a virtual village is needed for people aging with HIV, it can also serve as a model for reducing health inequalities critical for a society prepared to survive future pandemics by establishing a means of providing continued access to medications, to services such as telemedicine, to food delivery, and to counter social isolation through connections with their communities.

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