Study Reveals Delays, Copays and Stigma for HIV-Positive People in Jail

People living with HIV often come from heavily policed neighborhoods. HIV criminalization laws compound this disparity.

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Less than half of people living with HIV who had ever been in jail reported their health care was sufficient, according to a small study published in the journal PLoS One. These findings suggest more must be done to ensure continuity of HIV care when people are incarcerated.

People living with HIV (PLWH) are disproportionately impacted by mass incarceration. And laws that criminalize alleged nondisclosure of HIV status or add additional charges for people with HIV increase the burden of incarceration for this population. While there has been research on how people living with HIV receive health care in prison, there hasn't been much research on how HIV-positive people are treated while in local jails.

So between March 2019 and March 2020, Colleen Blue, MPH, a researcher with the Institute for Global Health and Infectious Diseases at the University of North Carolina at Chapel Hill, and colleagues conducted interviews with 23 people living with HIV who were currently or had been incarcerated in jails in North Carolina. Ten of them were out of jail, while 13 were interviewed while in custody.

The participants were primarily Black men, and slightly less than half were between ages 45 and 55. Two participants were women of trans experience. A majority of participants (70%) had at least a high school education. Another 70% had been living with HIV for at least 11 years. About half had had fewer than five jail stays since being diagnosed with HIV, but one in three had been in jail more than 10 times.

When Blue and colleagues asked participants about their access to HIV care while in jail, there was no consistent response. But just 30% said their care while incarcerated was satisfactory.

Almost half said their HIV care while incarcerated was insufficient due to delays in access to medication and medical appointments. Even more, 60%, reported delays in accessing their HIV medications because they were in jail for only a short period, had difficulty getting the right antiretrovirals or jail staff said they couldn't afford to provide appropriate medication. Still, most people eventually accessed medication; indeed, 78% reported that they were ultimately able to

get their antiretrovirals while in jail.

One participant suggested that it was harder to access medications in jail compared with in prison, noting that "the county's not like the state."

"The state would foot the bill because you're going to prison," one man said. "But the county don't want to foot that bill. Well, they would say that when you got medication at home, we'll call somebody and tell them to bring it."

Indeed, half of respondents said family members brought them medication in jail. And others said they managed the risk of jail time by carrying a pill case with them at all times so they'd have at least four doses of medication to bridge delays in access. But one man reported going without his antiretrovirals for the full 60 days he was incarcerated.

Still others chose not to take medications while in jail. One woman reported that the gastrointestinal side effects were hard to manage in jail, where she didn't get enough food to eat with her pills and where she didn't have ready access to a bathroom.

Most participants saw a clinician while in custody, but some couldn't receive care because they were required to contribute a co-pay of between $5 and $20, which they couldn't afford. When they did get care, they reported that their clinicians tried to connect them to resources and treatment once they were released.

When people left incarceration, their experiences getting reconnected to care were also highly variable. For some, it led them to get back into HIV care. But for others—nearly half—it disrupted their HIV care by delaying access to medications.

Almost all participants chose to keep their HIV status private from other incarcerated people, and more than half kept it private from nonmedical detention staff, for fear of stigma or violence. Two participants reported that having been in jail changed how their clinicians saw them. In one case, a man reported that he didn't talk about his HIV status with clinicians or take medications during his stay because jail staff were within earshot.

How universal these experiences are for people living with HIV in the criminal justice system is unclear, since the sample size is so small. But Blue said it's clear that more needs to be done to adapt existing programs, like the Data-to-Care (D2C) collaborative, to step in to provide medications and take that job out of the jail's hands.

"Expansion of community D2C services has the potential to preempt or at least alleviate jails' roles as de facto HIV safety net providers," wrote Blue and colleagues. "Findings from this study suggest that jail leadership should review internal policies regarding HIV medications to ensure that PLWH can receive them quickly upon entry into jail. Findings also suggest that more external resources are needed—for example, from state and local health departments—so that jails can provide timely HIV medications for PLWH incarcerated in their facilities."

Click here to read the full study.

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