

## Impact of the COVID-19 Pandemic on HIV Patient Engagement, Health Care Utilization, and Medication Adherence: A Mixed-Methods Study

### Summary of Findings

People living with HIV need to stay engaged in health care to support antiretroviral therapy (ART) adherence and manage their condition. The COVID-19 pandemic disrupted access to health care for many people.

The Brookdale Center for Healthy Aging and Amida Care conducted a two-part study to learn how the pandemic affected health care use for people living with HIV. In the first part, we analyzed Amida Care claims data from over 3,000 members to understand patterns of health care use from 2018 to 2022. In the second part, we interviewed 40 people living with HIV about their experience with health care during the pandemic. We asked what kinds of things interfered with their access to health care and medications, and what kinds of things made access to care easier. We also asked how the pandemic had affected their health and well-being.

We looked at patterns of primary care provider (PCP) and behavioral health visits, both in-person/office and telehealth over time. We used an analysis strategy to track changes in visits over time. Telehealth visits were reported beginning in February 2020, and made up 8.8% and 22.5% of PCP and behavioral health visits, respectively.

Results showed that PCP office visits were stable pre-pandemic, decreased sharply at the start of the pandemic, and gradually increased. During the pandemic, PCP office visits never reached pre-pandemic levels or stability. Behavioral health office visits showed a similar pattern. Sharp increases in telehealth use were observed around March 2020, for both PCP and behavioral health visits. Telehealth visits of both types decreased as the pandemic progressed.

Our interviews presented a similar story. Especially at the beginning of the pandemic, doctors' offices were shut down, and access to care was disrupted and delayed. For months, medications were sometimes out of stock, which affected the ability to stay adherent to HIV regimens. Study participants said staff shortages and changes in staffing affected the quality of care. Behavioral health services, such as therapy, mostly switched to telehealth if they were available at all.

Still, most participants were able to stay in touch with their PCPs by phone or video calls, even if waiting time increased. Many participants kept getting their medication with no problems throughout the pandemic.

People experienced stressful situations during the pandemic for many reasons. Study participants worried that having HIV increased the danger of COVID. Family members and friends died. People lost jobs and sometimes housing. It was a time of chaos, and people felt isolated, bored, and stir-crazy. The

disruption of routines could make it easy to forget your medication, and some people coped with the pandemic through substance misuse, which often led to other problems.

Overall, participants were resilient. Many had learned how to cope in a crisis, and they managed to maintain a positive attitude, especially with the help of friends and family. Others did not feel they had recovered yet.

Having good relationships with their health care providers made a difference in access to care. Good communication was especially important. Some participants had little or no disruption because they received all their care at one location. Having the option of video calls and phone calls helped a lot, but many participants were glad to go back to in-person visits.

For people living with HIV, staying engaged in care often involves a whole support system beyond doctors and nurses. Having a reliable pharmacist, a caseworker, a connection to community programs, and a network of friends all help during times of crisis. Some participants missed the HIV community services that shut down their in-person meetings, but others were able to stay in touch with Zoom meetings or outdoor gatherings. Several participants who recently moved to New York City said the support system was stronger here than where they came from.

We interviewed participants in the fall of 2023, more than three years after the pandemic began. Life had gone back to normal for some but not for others. Some changes felt permanent in the health care system and in everyday life, especially social life. For example, there was a sense that video instead of in-person interactions have become the norm. Some participants felt they themselves had changed, and some had lasting health problems, including long COVID.

## **Conclusions**

As expected, the COVID-19 pandemic caused a drop in primary care office visits and behavioral health care visits. Telehealth substituted for some of those visits, but as of July 2022, health care use was still lower than it was before the pandemic.

Interview participants were frustrated when they could not reach their doctors. Health care providers who want to help their patients stay engaged in care should make a priority of strengthening communication. There are many ways to do this, and different approaches work for different people. Technology can help a lot, but listening to patients and building relationships with them is even more important. Behavioral health may need extra attention during a crisis such as a pandemic, and it has not yet recovered. Providing a space to talk, even if it's not a formal therapy session, can help people feel connected.

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For more information, visit <https://brookdale.org/projects/impact-of-the-covid-19-pandemic-on-hiv-patient-engagement/>