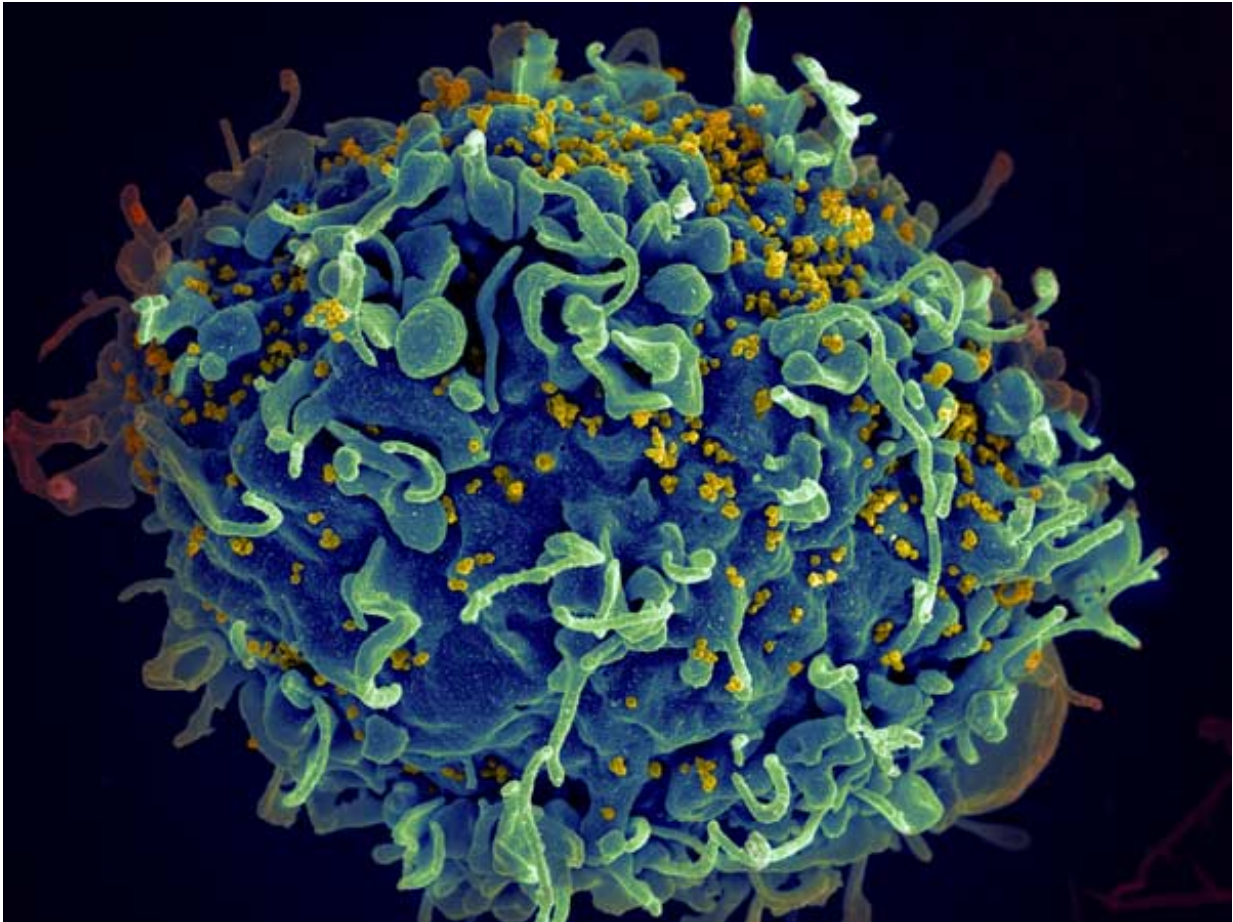


Living with HIV during a global pandemic

May 11 2021, by Beth Miller



HIV infecting a human cell. Credit: NIH

The impact of the coronavirus (COVID-19) pandemic has been profound for Delawareans living with HIV, according to a new report from the University of Delaware-based Disaster Research Center.

Researchers interviewed 55 Delawareans living with Human Immunodeficiency Virus (HIV) in January and February, focusing on those in greatest need of economic and health-care assistance. The goal was to gather accounts of their experiences, what they observed, needed, lost, wished had been different and found most helpful.

Many responses were similar to those of a general-population study DRC did last summer, said Tricia Wachtendorf, director of the center, with many reporting a deep sense of isolation, declines in physical or mental health, increasing economic hardship and uneven access to health care.

"Many of the issues we heard would be familiar to all of us," Wachtendorf said. "Layoffs, isolation, helping children or grandchildren with remote learning. They put off going to the dentist and even having surgery. But 13% had missed medication and 20% missed or delayed routine HIV lab tests."

Those disconnects are important for anyone concerned about improving care and developing plans for future crises.

Many living with HIV are ahead of the curve when it comes to coping with a potentially deadly virus. They already know the importance of trusted sources, accurate information, reliable testing and consistent medical care. Many also know—all too well—the heart-rending effects of distance and disconnection.

"One thing that really struck us, compared to interviews we did last summer, was that many participants in the HIV study were much more likely to use words like 'fear' or 'scared' when describing COVID-19, as opposed to 'anxious' or 'concerned,'" Wachtendorf said. "They realized the potential for this to be life threatening."

For that reason, most said they took public health guidelines seriously.

"The fear they talked about didn't result in a sense of helplessness," Wachtendorf said. "Instead—to the extent possible by finances and living arrangements—the participants described taking a lot of actions to protect themselves against the virus. It wasn't an afterthought."

This kind of information adds essential context to the data Delaware already has on its residents living with HIV, said Jordan Hines, manager of community planning for the [Delaware HIV Consortium](#).

Numbers and data are important, of course, and a comprehensive collection of data is included in [Delaware's 2020 HIV Surveillance Report](#).

More than 3,400 Delaware residents were living with HIV at the end of 2019, according to the state's report. Wilmington had the greatest number of cases and Black men accounted for more than half of all Delaware cases, but the virus resides in all ZIP codes, among all races, ethnicities and across all demographics. Suppression efforts have slowed the spread of the virus, but more than 2,000 people have progressed to the disease known as Acquired Immune Deficiency Syndrome (AIDS).

The DRC study, done at the request of the consortium, adds qualitative insight to those numbers, giving voice to the backstories and nuanced contexts represented.

"Delaware is so small, we can always work on the quality of our data," said Tyler Berl, executive director of the consortium, who earned his bachelor's and master's degrees at UD. "Qualitative studies improve our findings here. And having a research institution like DRC involved adds credibility."

The study required extended conversations, some lasting more than two hours. The consortium, which has more than 400 members, helped DRC

researchers connect with willing participants.

Connection was a frequent theme of these conversations.

"Connection—whether virtual or the lack of connection one-on-one—is what stuck out to me," Hines said. "This pandemic was new to everyone, not just the demographic we serve. It was new across the board.

Everyone struggles trying to move into a virtual world—whether that is meeting with doctors, having an assessment, feeling like you're not really getting served.

"Some shared that they had mixed feelings meeting with a doctor virtually. Or that they couldn't meet virtually and they were not comfortable going to the hospital or going to a doctor's appointment."

That may point to a need to invest more in telehealth, Hines said.

"This can help us—as a society and especially our demographic—recognize what the needs are should this come up in the future," Hines said.

Financial insecurity was another frequent theme. Some lost part or all of their income and had insufficient savings to tide them over.

"When there is a shock to the system, there are a lot who are already near the cliff financially," Berl said. "They can easily fall off that cliff at a time like this."

Every person's situation is different, and the pandemic demonstrated again that even shared experiences have significantly different impacts on people.

"We should never think about a community of people as entirely

vulnerable," Wachtendorf said. "Although they contend with a lot of vulnerability, there are many ways this community has shown strength to overcome very difficult circumstances throughout 2020."

As many COVID patients learned, stigma can be visited on anyone who contracts a communicable disease. That sense of stigma is not new to those living with HIV.

"We've always dealt with a lot of stigma," Berl said. "And testing has always been stigmatized. This is another virus that has stigmatized other populations, including the Asian population. Hopefully, normalizing testing will bring down some of these stigmas. Anything we can do to break the stigma of HIV is important to us and to our clients."

With COVID-19 spreading quickly, many stopped going to community-based testing sites that offered HIV testing. Testing was down by more than 50%, Berl said.

But now that the need for COVID-19 testing is recognized as critical for public health, why not have one-stop testing sites that cover multiple conditions?

"We hope to see COVID testing sites evolve to where they test for more than COVID," Hines said. "We're slowly getting to some kind of normalcy, but we should take advantage of all of that testing and test for opioids, hepatitis C, HIV. This study highlights the need to get tested across the board for any and everything, not just for this moment."

Two doctoral students—Christopher Tharp and Nancy Rios-Contreras—who conducted interviews for DRC said the experience was important for them.

"During the interviews, I heard— and in many ways connected with—

feelings of deep isolation in the experiences recounted by the people we spoke with," Tharp said. "The isolation was often expressed through stories of powerful, self-reliant resolve; but it was also often expressed in stories of grief and even, sometimes, loneliness."

All of that helps to bring a global disaster into personal focus.

"The collaboration between the Delaware HIV Consortium and the Disaster Research Center allowed me to explore how a global pandemic connects to the local community experience," Rios-Contreras said.

Direct quotations from some participants are sprinkled through the report.

One expressed the hope that has made the long struggle against COVID worthwhile.

"It's a sacrifice worth taking [protective measures and isolating] because I'm looking at the light at the end of the tunnel. I'm looking at the end of the road. And I would rather be here and healthy, than not."

Wachtendorf found those words impressive.

"We've seen so many other people out in the community not taking protective guidance seriously, not appreciating that their actions do impact others," she said. "The Delawareans living with HIV with whom we spoke took COVID-19, as well as the responsibility to protect themselves and others, very seriously."

More information: [Delaware's 2020 HIV Surveillance Report](#)

Provided by University of Delaware

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