Late HIV Testing

The earlier that a person learns his or her HIV status, the better. Early medical treatment can improve health outcomes in HIV-positive people, and HIV counseling and testing interventions can reduce the spread of the virus. Yet, between 24 and 45 percent of people who test HIV-positive are what researchers call “late testers.” A “late tester” is defined as someone who receives an AIDS diagnosis within a short period of first testing positive for HIV. Researchers sometimes use the term “late testers” to refer to different groups of people—including people who find out they have HIV and AIDS at the same time, people who develop an AIDS-defining condition up to a year after HIV diagnosis, and everyone in between. By this definition, about a third of new HIV diagnoses are among late testers.

Why Is Late Testing a Problem?

Despite this variety of standards, there is consensus among researchers about the stakes involved in testing late. Compared to those who find out their HIV-positive status earlier, late-testing clients are more likely to already have advanced opportunistic infections at the time of diagnosis. If and when they start HIV treatment, they are more likely to become resistant or react badly to their treatment regimens. All of these outcomes can lead to much higher death rates, and greater costs for medical care.

People who are unaware that they are HIV-positive are also much more likely to transmit HIV to others. After being diagnosed, most HIV-positive clients dramatically reduce their HIV risk behavior. Further, diagnosis often leads to treatment, which usually decreases a patient’s viral load. This means that HIV becomes much less transmissible during higher-risk activities.

Who Tests Late and Why?

Over the past 10 years, researchers have attempted to pinpoint who is testing late and why. Many studies have found that men who have sex with men (MSM) and injection drug users generally do not test late. There may be several reasons for this: people in these “high-risk” populations may be more aware of HIV as a concern; they are targeted by outreach and HIV-related services; and they may thus have better access to and community acceptance of testing.

Groups that are more likely to receive a late diagnosis include: heterosexual males; people under 30 and over 60; people not routinely offered HIV testing; people with either private insurance or no insurance; foreign-born people; and people who do not know how they became infected. CDC Surveillance Reports and other studies have also found that a greater percentage of people in non-White racial and ethnic groups, especially African Americans and Hispanics or Latinos, received AIDS diagnoses in close proximity to their initial HIV diagnosis.

This is despite the fact that in a large national survey, the Kaiser Family Foundation found that African Americans and Latinos are significantly more likely to report having been tested for HIV than are Whites.
A small University of Washington study of MSM explored the related phenomenon of “delayed testing” — testing that occurs more than a year after the person became infected with HIV. These researchers found that many of the delayed testers in their study did not originally recognize that they were at risk for HIV, possibly because they tended to be less sexually active with male partners. Many did not identify as part of the gay and bisexual community. This may suggest that community norms and awareness are an important part of encouraging HIV testing. Men who were not delayed testers also expressed greater willingness to share their HIV status with others, including family, friends, and sexual partners.10

People test late for a variety of reasons, which may include fear about or denial of HIV status, lack of knowledge about HIV/AIDS, and lack of awareness about or access to prevention and care services.1,10 In the University of Washington study cited above, homelessness was another factor associated with delayed testing status. Access is particularly difficult for socially and economically marginalized groups, people without insurance or regular medical care, those born outside the country, and poor people. Unfortunately, stigma around HIV still exists, and can keep people from testing for fear of judgment and ostracism.

What Can We Do About Late Testing?

More routine HIV testing in health care settings could greatly reduce late testing in the United States by periodically screening all patients. Some critics, however, argue that this strategy might divert resources away from other, more cost-effective interventions. Other interventions include improving the availability of testing for people in “high-risk” groups; using partner notification services, social networks, and peer outreach to disseminate information about HIV and testing; matching services to the personal and cultural needs of the clients;4 targeting some prevention messages to all men, not just men who identify as gay or bisexual;10 and minimizing barriers to testing, for example by expanding rapid testing in non-conventional settings.1 Medical providers who understand the importance of HIV testing, and who know how to talk nonjudgmentally about sex, sexually transmitted diseases, and substance use can also reduce the stigma that creates a barrier to testing for many.13

References