

Reducing Delayed Diagnosis of HIV

A fact sheet for health care providers and AIDS service organizations

Early HIV diagnosis saves lives

If diagnosed and treated early, people living with HIV are able to take advantage of life-extending medications and reduce HIV transmission up to 96%.¹ This fact sheet identifies some reasons for delayed diagnosis and suggests steps that health care providers and AIDS service organizations may take to encourage regular HIV testing.

Why are people diagnosed late?

To understand factors contributing to delayed diagnosis in Oregon, the Public Health Division of the Oregon Health Authority (OHA) conducted interviews with 17 people who met criteria for AIDS within 12 months of their HIV diagnosis during 2008–2010.² The brief period between HIV and AIDS diagnosis may indicate participants were infected, undiagnosed and untreated for 7–10 years.³

Three themes emerged from the interviews:

- 1) Failure to identify risk for HIV
- 2) Missed opportunities for diagnosis
- 3) Need for routine HIV screening

In Oregon, more than one-third (39%) of people diagnosed with HIV are diagnosed late (within 12 months of an AIDS diagnosis).

Theme 1: Failure to identify risk

“It will never happen to me.”

“The people I was with looked healthy.”

“I thought that I had a better chance of being pregnant.”

Many participants did not recognize their risk for HIV, even though they knew how HIV is transmitted.

Participants reported:

- A belief that HIV is something that happens to other people (e.g., gay people and people who inject drugs)
- A belief that one’s risk of becoming infected was low since most people do not have HIV
- Not knowing their partner’s risk behaviors
- Having an extended period of separation from their spouse
- Engaging in high-risk behaviors, sometimes for a brief period in one’s life

Theme 2: Missed opportunities for diagnosis

All participants were diagnosed with HIV after feeling ill for months to years and sought care due to illness. About half learned their HIV-positive status in an emergency room.

Most health care providers serving the participants did not offer HIV testing despite medical indication and recommendations for routine HIV screening. In only a few instances was HIV testing suggested. In these instances, participants did not get tested due to cost, administrative barriers, fear of an HIV diagnosis, or perceived judgment from a health care provider.

Some physicians appear to have overlooked the need for testing because the patients did not fit traditional “risk categories” or did not fully disclose their risks.

“ I started having issues with Candida infection. And the doctors kept giving me antibiotics . . . then it just came back again. ”

“ They tried to send me to a disease specialist, but they wouldn’t take me because I had to be referred from the primary care, not the emergency room. ”

Theme 3: Need for routine HIV screening

When asked what might have helped people like them get tested earlier, most participants recommended routine testing at physicians’ offices.

“ You get your cholesterol checked. You get your diabetes checked. Why not get this [HIV] checked? They would have caught me in the early stages. ”

Recommendations

The common theme emerging from the study is that health care and service providers should implement routine screening for HIV to circumvent unrealistic risk perceptions, reduce stigmatization of people who are tested and help diagnose HIV earlier. Learn more about routine screening recommendations at <http://bit.ly/HIVscreen>.

In addition, campaigns to promote preventive health care, even when people do not feel sick, would help to identify those at risk. Educational efforts that frame HIV as relevant to all populations and address outdated stereotypes and perceptions of HIV risk would benefit both the public and providers.

Find more information about delayed HIV diagnosis in Oregon at www.healthoregon.org/hivdata.

1. Cohen MS, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *NEJM*. 2011, 365.
2. Schwartz, SL, Block, R, Schafer, S. Oregon Patients with HIV infection who experienced delayed diagnosis. *AIDS Care*. 2014. In press.
3. Oregon Health Authority, Public Health Division, HIV/STD/TB Program, *Epidemiological Profile of HIV/AIDS in Oregon*. July 2013.

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