Should the HIV Care Continuum Include Leaving Care?

The current design of the HIV care continuum is a straight line from diagnosis to an undetectable viral load.

July 7, 2021 By Heather Boerner

In a PLoS Medicine commentary, an international consortium of global HIV grant makers, researchers and clinicians are asking an unusual question: Should the HIV care continuum include people leaving care?

Right now, the HIV care continuum includes three steps: being diagnosed with HIV, being linked to care and achieving an undetectable viral load. This definition is used by everyone from UNAIDS to your doctor's office.

This is important because data show that when people achieve an undetectable viral load, they are healthier, have fewer HIV-related illnesses and don't pass HIV on to their sexual partners. Plus, when a whole community of people is undetectable, it reduces the risk of HIV for everyone.

UNAIDS had set a goal of 90% of people with HIV diagnosed, 90% of those on treatment and 90% of those with viral suppression by 2020—the so-called 90-90-90 targets. That didn't happen, and now the goal has been advanced to 95-95-95 by 2030.

But in the commentary, Peter Ehrenkranz, MD, MPH, of the Bill and Melinda Gates Foundation, and colleagues call this an oversimplification.

"This simplification of this cascade oversimplifies the complex cycle of engagement, disengagement, temporary disruptions, reengagements and transitions in care experienced by many people living with HIV," they wrote. "We propose the introduction of an HIV cascade of care that better captures the nonlinear HIV journey."

The new cascade has five stages:

- HIV diagnosis or re-diagnosis
- Linkage or re-linkage to HIV care

- Initiating or reinitiating HIV medications
- Early engagement in care for six months or less
- Long term retention in care for more than six months.

Between each stage is a feedback loop that acknowledges that some people don't enter care, start treatment or stay in care in the way that the continuum implies now.

"By explicitly capturing [people with HIV] revolving into and out of each of the stages of care, it becomes possible to both pose and answer novel questions," wrote Ehrenkranz and colleagues. "What is the frequency of repeat exit and reentry? Which stages most correlate with return without intervention versus as a result of an intervention? What are the implications of loss/reentry at a given stage on future losses? Failure to answer these questions can impede our ability to develop effective interventions to support continuity of care and effectively utilize available resources."

The current cascade made sense before the move to rapid or same-day HIV antiretroviral therapy (ART) initiation, which has been found to speed time to an undetectectable viral load for people who have the support to create a durable relationship with an HIV provider. But now, "rapid, including same-day, ART initiation…essentially eliminates losses from care before ART initiation." This, they write, shifts the time when people leave care from before even starting HIV treatment to after. Plus, the commentary states, sometimes the expectation that people will start HIV treatment and stay on it leads people to avoid returning to the same clinic. A nonlinear cascade of care would allow health care providers and nonprofits to more accurately judge how well they are doing in supporting people to get to undetectable and stay there, whether they are starting medication for the first time or for the ninth.

The revolving door of care may also be an equity issue. Black Americans, for instance, are most likely to test positive for HIV but least likely to achieve an undetectable viral load. Understanding the disparities in disengagement and reengagement in care could allow funders to work with clinics to identify where the clinic is doing a poor job interacting with people with HIV so they can improve.

"Maximizing retention across the cascade will require recognizing the factors leading to disengagement—structural, clinic based, and individual—and ensuring that they are systematically addressed by providers, communities, and health systems," the authors wrote.

Click here to read the full commentary.

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