

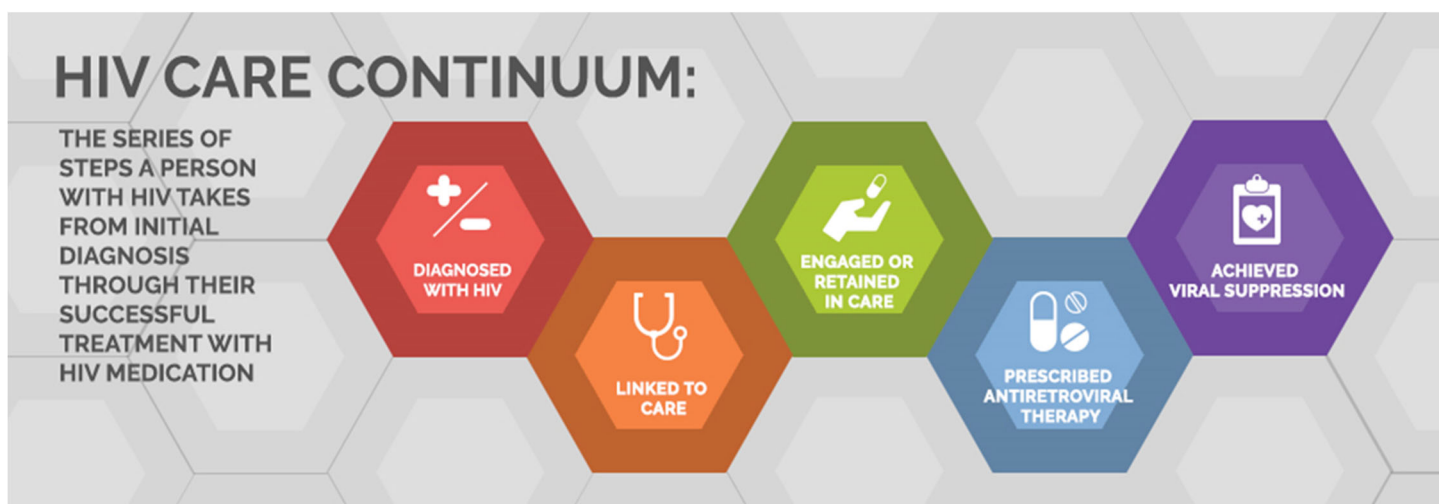
Community-Based Study of the Rural HIV Care Continuum

What did we want to find out? What is the lived experience of being in and going through the rural HIV care continuum among rural gay and bisexual men (GBM) living with HIV in a rural region of a Midwestern state.

- What is it like to be in and go through the rural HIV care continuum?
- What does it mean to be in and go through the rural HIV care continuum?
- What does the rural HIV care continuum mean?
- What are the characteristics of being in and going through the rural HIV care continuum?

What is the HIV care continuum? The HIV care continuum is a series of steps a person goes through to manage their HIV. We asked people questions what their experiences were with each of these steps. For example,

- What were you thinking when you heard you were **diagnosed** with HIV?
- Did someone talk to you about HIV resources? What were you thinking when you were **hearing these resources**?
- Can you tell me about your experiences **using services** at your AIDS service organization?
- What are experiences **taking HIV medicine**?
- What did you think when you heard you were **undetectable**?



Why did we ask these questions? There are a couple of reasons why we did this study

- Our community partner was interested in this question.
- Most HIV care continuum research collects data on people with HIV who live in metropolitan cities, and a few collected data on people living with HIV who live in rural areas.
- Most HIV care continuum research collects data on 1 of these stages (example, only taking HIV medicine) rather than all the stages. There are only 3 studies that explore the experiences of going through all these stages, and all collect data on those who live in metropolitan cities

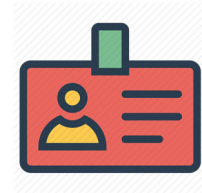
How did we collect and analyze data?

- The researchers and the participants had a telephone interview that lasted approximately 1 hour.
- Participants were given a \$30 gift card of their choice as a thank you.
- We were looking for themes that were found throughout all interviews
- 15 rural GBM living with HIV who live in a rural region of a Midwestern state participated.



Demographics

- Average age = 47 years old
- Non-Hispanic White = 100%, n = 15
- Single relationship status = 67%, n = 10
- Cisgender men = 100%, n = 15
- Gay = 93%, n = 14
- Employed full-time = 40%, n = 6
- Annual household income under \$20,000 = 40%, n = 6
- Associate's or bachelor's degree = 40%, n = 6
- Diagnosed with HIV pre-2011 = 73%, n = 11
- Male-to-male sex transmission = 100%, n = 15
- Ever injected drugs that were not used for medical purposes = 27%, n = 4
- Ever injected an opioid = 7%, n = 1



Diagnosis meant death

When participants heard they were diagnosed with HIV, they thought HIV was a death sentence, and they were going to die from AIDS-related complications soon. They thought this based on what they saw on television, saw their friends and family with HIV dying from AIDS-related complications, and the limited HIV medicine options available.

"I thought I would be on those people that would die. It was just a matter of time. There was cocktails and things, but if those don't work, then the last one they can do is intravenous. If that doesn't work, you die." (#4)

Linkage to care meant uncertainty

Participants were unsure of their next HIV care steps and unsure if they could live normal, healthy, and long lives. The linkage to care meant uncertainty as participants said they were not linked or referred to care; they were only told they were diagnosed and needed help but no reference to organizations. Instead, many of their friends living with HIV connected them to HIV care resources.

"The county health department tested me, told me I need to get treatment, and then I was done and on to the next patient. I felt like cattle on auction just going through. I had to talk to a friend of mine that is positive, and he told me to go to [AIDS service organization]. There should have been someone who sat down and said here are the possibilities and resources." (#5)

Care improves quality of life

Participants faced a variety of social factors (e.g., unemployment, housing insecurity, no insurance) and health factors (e.g., depression, addiction, heart disease) that impacted their lives before they were diagnosed with HIV, as well as after they were diagnosed with HIV. Participants felt using HIV services and interacting with their HIV service providers improved their quality of lives.

“After I’d lost my job and my roommate overdosed, I didn’t know how I was going to keep this house ‘cause it was \$620 a month. I couldn’t have paid that myself. [My HIV service provider] called my landlord and said they’re gonna pay my rent. They also helped me with Section 8 housing since my job is seasonal. They also helped me get jobs, helped me build my resume, and those kind of things. This program is a game changer.” (#8)

Taking HIV medicine means life

Participants initially thought HIV meant death, but they thought taking HIV medicine daily means they could live—live a normal, healthy, and long life. They saw their friends with HIV who took their medicine daily live, while they saw their friends who were not taking HIV medicine daily die.

“I knew people that were positive who were on their meds and doing well and living a good life. And then I had other friends that weren’t taking their meds and got sick or are dead now. I made a choice that I’m going to take my meds to take care of myself. People used to die from this, but now I take medication that keeps me alive.” (#3)

Participants mentioned that HIV medicine did not always mean life. Early HIV medicine meant death due to the severe side effects, adverse side effects, limited options, and uncertain effectiveness.

“I started out on AZT, and I can remember having to crawl on my hands and knees to the bathroom ‘cause I was so sick. It was like taking rat poison. I stopped taking it—I would rather just try to live and die than take this medication. You became scared because, at that time, there wasn’t anything else. What if I get sick? Am I gonna die? In the beginning, HIV meds was just a trial and error. So you spent that whole time thinking it was working, but your T-cells were dropping, and your viral load was going up. You had to start over again.” (#11)

Undetectable affirms taking HIV medicine daily and control

Participants felt that them taking HIV medicine daily was benefiting them, and having an undetectable status provided them more control over lives and certainty that they could live a long, normal, and healthy life.

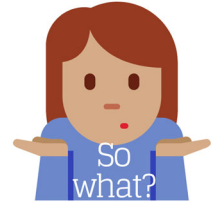
“Hearing I was undetectable was a big weight lifted off my shoulders. I’m gonna survive. You’ve got time.” (#10).

A part of a “normal” life was dating, but 12 participants (80%_ mentioned they encountered dating stigma after they were undetectable.

“I’ve been turned away before for being undetectable on apps. It can be a little disheartening. I’ve had people say to me that although I’m undetectable, they can’t trust me ‘cause they don’t know if I’m taking my meds correctly. I don’t think undetectable equals untransmittable means that everyone’s completely comfortable with having sex with an undetectable person. There’s such a social stigma around it.” (#15)

So what?

- Since participants (including all those diagnosed after year 2016) experienced negative linkage to care experiences, awareness of HIV services, and referral to HIV services, future research is needed to examine the acceptability, feasibility, and effectiveness of a linkage to care mobileHealth or telehealth program in rural areas.
- Future research is needed to determine HIV knowledge and stigma among rural populations, and results could be used to inform an HIV knowledge and stigma reduction program rural areas.
- Future research and programming is needed to address HIV dating stigma from the perspective of people with an HIV-detectable status, people with an HIV-undetectable status, and potential dating and sexual partners.
- Since rural areas face a shortage of social, human, HIV, health, and mental health care services, policies are vital to create, fund, and sustain HIV organizations that provide comprehensive services that address a variety of services and navigation (e.g., housing, employment, insurance, HIV medicine access, addiction counseling).
- Given participants experienced a variety of factors (e.g., housing insecurity, unemployment, addiction, depression, chronic pain, heart disease), having social workers be involved in the decision-making process at a local, state, and national level could better assist outcomes (e.g., referral outcomes, engagement outcomes, retention outcomes).
- How else to measure the success of the HIV care continuum than only using HIV testing measures? How to revise a medical model to include psychological, social, and psychosocial concepts (e.g., mental health, housing security, stigma)?



Hold on—Limits?

- Findings cannot be generalized to the lived experiences of GBM living with HIV who live in the U.S.—or the region of the state under investigation.
- The sample size (n = 15) and similar characteristics of the sample (everyone had similar demographics) limited our ability to observe differences among different demographic characteristics.
- Most participants (73%, n = 11) were diagnosed with HIV pre-2011. Looking at those recently diagnosed with HIV (after year 2016), there wasn't any differences in themes. The time of diagnosis matters given the advancements in HIV treatment and coordination of HIV care services.

Acknowledgments

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